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# The Suitability of Online Tinnitus Information

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## Acknowledgements

*“I panicked and didn’t write a speech and accidentally thanked the entirety of New Zealand in my speech”*

— Rose Matafeo, on winning the Best Comedy Show at the 2018 Edinburgh Fringe Festival.

When reflecting on completing my study to become an audiologist, completing this thesis and also reflecting more broadly on my time at university in general, I came across this quote that made me laugh – my audience for this body of work is definitely a more of a niche crowd.... and the content may not be quite as award worthy or entertaining, however I too would like to acknowledge a few whānau for their support - short of thanking the entirety of New Zealand.

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## **Abstract**

**Purpose:** The aim of this study was to investigate the suitability of English language online tinnitus information, as identified and assessed by Manchaiah et al. (2017). The study also analysed the relationships between suitability and three other factors: website origin, quality and readability.

**Method:** The SAM tool (Doak, Doak, & Root, 1996) was used to assess suitability. Before using the SAM tool to rate the tinnitus websites, the researcher and a second researcher performed SAM ratings on non-study material to ensure satisfactory reliability. In total, 37 randomly selected webpages from three separate origins (Commercial = 14, Non-profit = 11, Other = 12) were analysed.

**Results:** This study found the suitability of online tinnitus information to be adequate. Common areas of greater suitability were literacy demand and items within layout and typography. Common areas of poorer suitability were content, graphics, learning, stimulation and motivation and cultural images and examples. No webpage origin was found to be creating content of higher suitability than another, higher suitability was not correlated with quality and more suitable webpages were not found to be associated with lower readability.

**Conclusions:** The results of this study indicate more effort is required from developers of online tinnitus material to develop materials of superior suitability and that hearing professionals must be aware of the suitability of the materials they recommend (and adapt them if necessary) to ensure materials are suitable for individuals seeking tinnitus information online. By developing and using information that is of superior suitability, there is greater potential for individuals with tinnitus, and their family and friends, to effectively inform themselves, manage their symptoms and improve their health outcomes, especially for individuals with lower health and eHealth literacy.

## List of Abbreviations

AAO-HNSF American Academy of Otolaryngology—Head and Neck Surgery Foundation

ANS Automatic Nervous System

ANOVA Analysis of Variance

CBT Cognitive-behavioural Therapy

CNS Central Nervous System

ccTLDs Country-coded Top-Level Domains

ENT Ear Nose and Throat Specialist

F-K Flesch-Kincaid Grade Level Formula

FRES Flesch Reading Ease Score

GP General practitioner

GPG Good Practice Guide

HON Health on the Net

iCBT Internet-based Cognitive Behavioural Therapy

ICC	Intra-Class Correlation
PCC	Patient Centred Care
RGL	Reading Grade Level
SAM	Suitability Assessment of Materials
SES	Socioeconomic-status
SMOG	Simple Measure of Gobbledygook
UK	United Kingdom
US	United States of America

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## **Chapter 1: Introduction**

### **1.1 Tinnitus**

#### **1.1.1 Definition**

Tinnitus is the perception of sound in the absence of an external acoustic sound source.

Therefore, while individuals may link tinnitus to the concept of “hearing” sounds, it is most often an entirely internal phenomenon (S. C. Brown, 1990; A. Davis, 1995; Henry, Dennis, & Schechter, 2005; Hinchcliffe, 1961; Leske, 1981; Sindhusake et al., 2003; Tunkel et al., 2014). Individuals may describe hearing their tinnitus from their ears while others describe hearing their tinnitus from within their head. Tinnitus may be unilateral or bilateral, continuous or intermittent (Langguth, Kreuzer, Kleinjung, & De Ridder, 2013), the characteristics of tinnitus varies person to person, but is most commonly described as a whistling, buzzing, ringing, hissing or humming sound (Henry et al., 2005; Parra & Pearlmutter, 2007).

#### **1.1.2 Pathophysiology**

Tinnitus is not a disease but a symptom that is associated with a variety of different causes and co-occurring factors (Tunkel et al., 2014) and may be symptomatic of a number of potential pathological changes spanning the length of the auditory pathway, from the outer to the inner ear and along the auditory nerve to the auditory cortex (Langguth et al., 2013). In some cases tinnitus may be idiopathic and the exact cause is unknown (Tunkel et al., 2014) however common causes include cerumen impaction in the auditory canal (Beck, 2017) and damage to the inner ear (Langguth et al., 2013; Møller, 2003). Damage to the inner ear may be caused by factors such as age-related wear and tear of the inner ear system, noise exposure, head injuries or ototoxic medications. Such damage can cause a subsequent

temporary or permanent reduction in auditory input (another way of saying hearing loss) which the inner ear may be responding to, and therefore an individual's perception of tinnitus is symptomatic of this damage (Rybak, 2005).

The relationship between tinnitus and hearing loss is slightly unpredictable. An individual may have tinnitus and no hearing loss, likewise, an individual may have hearing loss and no tinnitus. However, hearing loss and tinnitus often co-occur, and the frequencies where the hearing system experiences reduced auditory input generally corresponds to the pitch of an individual's tinnitus. For most individuals, higher pitched tinnitus is common, where age related, and noise induced hearing loss frequently occur (Parra & Pearlmutter, 2007).

Tinnitus may also be indicative of changes further up the auditory pathway from the inner ear. For instance, atypical changes to the auditory nerve (like a the growth of a vestibular schwannoma) may also result in the perception of tinnitus (Langguth et al., 2013; Møller, 2003). Additionally, tinnitus can be triggered, or exasperated, by heightened emotions and stress. In some cases, tinnitus onset is not caused by any one factor but a combination of factors. Hearing loss due to damage of the inner ear, in combination with abnormal central nervous system activity, possibility due to traumatic and ischaemic damage, and stressful life events and activities can all be contributing factors in the onset of tinnitus generation (Langguth et al., 2013).

#### **1.1.2.1 The Underlying Mechanisms of Tinnitus**

Two key models have been suggested to explain the underlying mechanism of tinnitus, the psychological approach and the neurophysiological approach (McKenna, 2004). These models are “suggested” at this stage, because while in some cases the cause of the tinnitus

onset may be unequivocal, the exact biologic and structural changes responsible for tinnitus is still not fully known (Henry, Roberts, Caspary, Theodoroff, & Salvi, 2014). Both models place the role of the brain and the automatic nervous system (ANS) at the forefront of the mechanism, any inner ear damage as a secondary factor, and habituation as a key step in its resolution.

#### **1.1.2.1.1 The Psychological Approach**

The psychological approach suggests there are three key factors involved in all individuals' experience of tinnitus: the central nervous system (CNS), the ANS and a system governing tinnitus habituation. Most importantly, it is a delay in the system of tinnitus habituation that results in troublesome tinnitus (McKenna, 2004). In the majority of instances where an individual experiences tinnitus, the novelty of these new sounds identified by the auditory system will soon wear off, the CNS will interpret these sounds as meaningless stimuli and this will result in habituation to tinnitus. However, in some cases, it may be that the tinnitus onset has triggered high ANS arousal – the fight or flight response. This may occur if the tinnitus onset is sudden, especially intense and especially if the CNS gives an emotional significance to the sounds (Hallam, Rachman, & Hinchcliffe, 1984). McKenna (2004) discussed that “some people believe tinnitus to be a natural part of ageing and experience no strong emotion about it. Others hold beliefs such as “this means that I have a serious illness”, “I can’t cope with this; I will go mad” or “it’s not fair that I have this”. Clearly, such beliefs are likely to lead to distress. In turn, a distressed emotional state can distort a person’s interpretation or beliefs about tinnitus (causing a negative feeling towards the tinnitus) and so perpetuate the distress”. In cases such as this, the typical process of the CNS filtering out these sounds is interrupted and habituation to tinnitus has is delayed.

#### **1.1.2.1.2 The Neurophysiological approach**

Likewise, the neurophysiological approach also places central processes at the forefront of tinnitus perception. This approach discusses that as a consequence of inner ear damage, the inner ear system creates more auditory gain to compensate for the restricted sound input it experiences, an action which presents as tinnitus. However in doing so, this activates the brain's limbic system (a regulator of emotion, learning and memory) and the ANS which triggers a fight or flight response to this new sound stimuli. Tinnitus may become problematic if paired with a negative association (causing prolonged activation of the ANS) i.e. if someone believes tinnitus indicates a serious health concern or that something is wrong with them (McKenna, 2004).

#### **1.1.3 Classifying Tinnitus**

Tinnitus should be classified as either primary or secondary according to The American Academy of Otolaryngology–Head and Neck Surgery Foundation (AAO-HNSF). Primary tinnitus is idiopathic and may or may not co-occur with sensorineural hearing loss. Secondary tinnitus is associated with a specific cause or identifiable condition such as cerumen impaction or Meniere's disease (Tunkel et al., 2014). Tinnitus is also classified as subjective or objective and pulsatile or non-pulsatile and according to its severity. Tinnitus is most commonly subjective, meaning the tinnitus is only audible to the individual. Alternatively, a small portion of individuals' tinnitus is objective, meaning it is audible to both the individual and the examiner (Ciocon, Amede, Lechtenberg, & Astor, 1995). In cases of objective tinnitus, the origin of these sounds may be vascular, muscular, respiratory, or originate from the temporomandibular joint (Henry et al., 2005). On rare occasions, tinnitus may beat in a rhythmic pattern, typically in time with the heart, this is called pulsatile tinnitus which is most commonly a symptom of an underlying vascular pathology (Waldvogel, Mattle,

Sturzenegger, & Schroth, 1998). In cases of either objective or pulsatile tinnitus, the underlying medical cause of the tinnitus warrants medical evaluation (Henry et al., 2005).

The acoustic characteristics of tinnitus vary considerably. Tinnitus may be a very soft sound, perceivable only just above an individual's hearing thresholds, or it may be a sound of high intensity that is very intrusive (Langguth et al., 2013). Despite this variance, in many cases it is the individual's attention (or inattention) to their tinnitus that is the most important factor in determining the degree of severity they experience. Mild tinnitus is rather common, reported by many individuals after a few minutes in a quiet environment and most people habituate to the sound (Langguth et al., 2013; Parra & Pearlmutter, 2007). In cases of more severe tinnitus, Henry et al. (2005) discussed that focus and preoccupation with tinnitus (hypothesised to be caused by activation of the fight or flight response in the ANS, paired with a negative emotions towards tinnitus) can produce a repeating cycle of annoyance and mood changes, fear, anxiety, and depression—all of which are associated with higher tinnitus severity. For 1 – 2% of people with tinnitus, their tinnitus is severe and highly impacts their quality of life (Langguth et al., 2013).

#### **1.1.4 Prevalence and Risk Factors**

For adults world-wide, tinnitus is a fairly common experience. Estimates based off epidemiologic studies from a variety of countries approximate 10-15% of adults experience tinnitus (S. C. Brown, 1990; A. Davis, 1995; Khedr et al., 2010; Lasisi, Abiona, & Gureje, 2010; Michikawa et al., 2010). A 2016 study, representing a sample of more than 220 million people, approximated the prevalence of tinnitus to be 1/10 adults in the United States (US). Of the participants surveyed, around a quarter had symptoms for more than 15 years and around a third experienced tinnitus nearly constantly (Bhatt, Lin, & Bhattacharyya, 2016).

Hearing loss (higher-frequency, steeply sloping hearing loss in particular), aging, male sex and regular exposure to noisy environments at work and during leisure time have been found to be the most relevant risk factors for developing tinnitus (Bhatt et al., 2016; Hoare, Kowalkowski, Kang, & Hall, 2011; Hoffman & Reed, 2004).

## **1.2 Management Strategies**

While many adults experience tinnitus, only a small portion seek help from hearing specialists or health professionals (Attias et al., 1995). Professional help is typically sought only in cases of severe tinnitus (1 – 2% of the population) when it is continually intrusive and seriously impacting quality of life (S. C. Brown, 1990; A. Davis, 1995; Hinchcliffe, 1961; Leske, 1981; Sindhusake et al., 2003).

In the United Kingdom (UK), the Department of Health developed the Good Practice Guide (GPG), a set of protocols to help guide the provision of services for individuals with tinnitus (Hoare et al., 2011). In the US, the AAO-HNSF has produced The Clinical Practice Guidelines, evidence based recommendations for clinicians to determine the most appropriate interventions to improve tinnitus symptoms (Tunkel et al., 2014). The AAO-HNSF guidelines provide a intervention recommendations (from low to high: an option, a recommendation or a strong recommendation) based on the quality of evidence supporting the evidence (A, B or C grade).

For the majority of individuals with tinnitus (primary, subjective and non-pulsatile), their tinnitus is a symptom of an underlying, non-life-threatening pathology of the auditory system. To date, there is no cure for primary tinnitus therefore it must be managed instead. The AAO-HNSF stresses the importance of patients knowing that while there is no cure for

their tinnitus, management strategies for tinnitus do exist that can improve their symptoms and relieve distress (Tunkel et al., 2014).

For individuals seeking professional help with tinnitus, their first point of contact is often with their general practitioner (GP) (Fackrell, Hoare, Smith, McCormack, & Hall, 2012).

Following an initial GP consultation, the GPG and AAO-HNSF recommend that patients who have non-troublesome tinnitus that co-occurs with hearing loss, should be referred directly to audiology services for management. Patients who report tinnitus that is distressing, unilateral, pulsatile or tinnitus with a suspected associated medical disorder should be referred to audiology and ear nose and throat specialist (ENT) services for further assessment as appropriate (Department of Health, 2009; El-Shunnar et al., 2011; Tunkel et al., 2014).

The GPG provides a clear protocol to guide tinnitus management, and the AAO-HNSF provides clinicians with evidenced based recommendations, however clinicians may lack awareness that these resources exist and are accessible online, and also resources like these do not exist in most countries. As a result of this health professionals report mostly using either a trial and error approach or applying a generic treatment method that is intended to work for all (Henry et al., 2005; D. Hoare, Gander, Collins, Smith, & Hall, 2012). Broadly, management strategies can be classified into: (a) sound therapy, (b) counselling, (c) a combination of a and b, or (d) cognitive therapies (D. Hoare, Broomhead, Stockdale, & Kennedy, 2015). In addition to these, this thesis will also discuss pharmaceutical management. The rationale for these strategies is largely based off a mixture of anecdotal evidence and expert opinion and a high quality evidence base for some of these strategies is lacking (Hoare et al., 2011).



### **1.2.1 Pharmaceutical Management**

Because tinnitus is a symptom that may indicate abnormality in any number of places within the auditory system, it is unlikely a single drug could be effective in suppressing every kind of tinnitus and multiple drugs would be required to target the various different underlying pathologies of tinnitus (Trellakis, Lautermann, & Lehnerdt, 2007). Pharmaceutical options have been investigated such as intratympanic lidocaine, carbamazepine and benzodiazepines (both anticonvulsants). These drugs all aim to suppress the neuronal hyperactivity that likely causes tinnitus (Goldstein & Shulman, 2003). To date, none of these drugs have a sufficient evidence base (i.e., high quality, double-blind, placebo-controlled studies showing efficacy) and effects are mostly transient with serious negative side effects. The AAO-HNSF states that “clinicians should not routinely recommend antidepressants, anticonvulsants, anxiolytics, or intratympanic medications for a primary indication of treating persistent, bothersome tinnitus” on account of these options having a low evidence base and avoiding false hope, side effects and unnecessary medication costs (Tunkel et al., 2014). No drug has been approved by the US Food and Drug Administration or the European Medicines Agency for the treatment of tinnitus (Langguth & Elgoyhen, 2012).

El-Shunnar et al. (2011) reported on GPs’ management of tinnitus in in UK and found 17% of respondents prescribed drug therapies as part of their tinnitus management strategy.

Antidepressants are often used in the treatment of tinnitus and are part of the GPG protocol (Department of Health, 2009). These drugs have no primary effect on tinnitus, however they treat co-occurring depressive or anxiety symptoms which has been reported to indirectly improve tinnitus (Baldo, Doree, Molin, McFerran, & Cecco, 2012).

## **1.2.2 Sound Therapy**

### **1.2.2.1 Masking**

Masking is a common management approach where another sound is used to “mask” out the tinnitus. In principle the masking sound is perceived as less disturbing or annoying than the tinnitus itself (Langguth et al., 2013). Sounds such as white noise, the sound of a waterfall or waves are commonly used. Masking devices can be worn behind the ear (and look similar to a Behind-the-Ear style hearing aid), they can be a small portable device, or a masking program is available in most modern hearing aids. Alternatively, everyday masking devices like smartphones, radios and CD players can be helpful (Tunkel et al., 2014).

The AAO-HNSF recommends sound therapy to patients with persistent, bothersome tinnitus as it may improve their quality of life, sleep and concentration (Tunkel et al., 2014). However some researchers report masking is rarely adopted by patients as a long-term management approach because it is simply replacing one auditory annoyance with another (Parra & Pearlmuter, 2007; Tyler, 2006). There may also be contraindications for using this treatment approach for patients with anxiety as masking may exasperate these feelings (Hoare et al., 2011). Additionally, the evidence towards the efficacy of using masking to decrease tinnitus perception and an increase in quality of life is low (Hoare et al., 2011).

### **1.2.2.2 Hearing Aids**

Hearing aids are worn by individuals with hearing loss to improve their quality of communication (D. Hoare et al., 2012) however, hearing aid use may have a secondary benefit of reducing tinnitus perception (Langguth et al., 2013). In cases of co-occurring hearing loss and tinnitus, hearing aid provision is exceedingly common. Hearing aids are thought to reduce tinnitus perception by: (1) improving quality of life related to hearing

difficulties, (2) reducing attention to tinnitus, and (3) enabling masking by surrounding ambient sounds (Coles, 1985; Del Bo & Ambrosetti, 2007; Parra & Pearlmutter, 2007). A 2009 survey of British audiology and hearing therapy staff found 99% of respondents reported fitting hearing aids as a management strategy (D. Hoare et al., 2012). The AAO-HNSF recommends a hearing aid evaluation for patients with hearing loss and persistent, bothersome tinnitus. The level of loss is unspecified because people across all levels of hearing loss associated tinnitus, from mild to severe, may benefit from hearing aid use (Tunkel et al., 2014). The application of this wide fitting criteria is clear not only in the US but also in the UK. A 2014 survey of tinnitus service provision in the UK that found clinicians recommended hearing aids for tinnitus on an individual basis, accounting for a patient's preferences and self-reported difficulties (D. Hoare et al., 2015).

Del Bo and Ambrosetti (2007) found new hearing aid wearers report a significant decrease in communicative stress and Surr, Montgomery, and Mueller (1985) found around 50% of participants reported a decrease in tinnitus perception as a result of hearing aid use. Therefore it follows that by making communication less stressful through hearing aid use, this may be decreasing symptoms of tinnitus (Del Bo & Ambrosetti, 2007).

However, a reduction in tinnitus perception may not be universal for all wearers. Schaette, König, Hornig, Gross, and Kempte (2010) and McNeill, Távora-Vieira, Alnafjan, Searchfield, and Welch (2012) found no benefit for individuals with tinnitus higher equal or higher than 6 kHz. At these high frequencies hearing aid amplification is limited due to technological capability and therefore the benefits of hearing aid use are not provided. This may be a useful counselling point for clinicians when considering this management strategy. Additionally, while hearing aid provision is a common management strategy for individuals

with tinnitus and hearing loss, evidence from high quality, controlled trials on the efficacy of hearing aids on tinnitus is low (Hoare et al., 2011; Langguth et al., 2013).

### **1.2.3 Informational Counselling**

Informational counselling involves helping individuals understand what tinnitus is, correct false beliefs, help normalize their experience and set realistic expectations (Langguth et al., 2013). Where appropriate, advice may also be provided on the potential side effects of tinnitus such as emotional distress, sleep difficulties, loss of concentration and attention problems (Langguth et al., 2013; Tyler, 2006). It is vital that individuals are told that there is presently no cure for tinnitus, however there are management strategies that can improve their symptoms and quality of life. The AAO-HNSF recommends counselling for patients with persistent and bothersome tinnitus and states benefits may include improved quality of life, increased ability to cope and improved outcomes (Tunkel et al., 2014).

Common counselling points to help manage tinnitus include: (a) avoiding high-level noise exposure, (b) removing lifestyle factors that may exasperate tinnitus (e.g., reducing stress, getting adequate sleep, limiting intake of alcohol, caffeine, tobacco), (c) maintaining a constant background of sound (avoiding silence) to reduce the prominence of tinnitus, and (d) staying busy with meaningful activities to distract attention away from the tinnitus (Henry et al., 2005; Tunkel et al., 2014).

It is evident counselling is a key component of any tinnitus management strategy as 96% of English audiology and hearing therapy staff reported providing counselling in a 2009 survey (D. Hoare et al., 2012). Additionally, the GPG states that counselling is sufficient treatment for many individuals, particularly individuals with milder forms of tinnitus (Department of

Health, 2009). However, while this is a widely used management strategy and anecdotal evidence may suggest its efficacy, high quality studies evaluating the efficacy of counselling have not been published (Hoare et al., 2011; Langguth et al., 2013).

#### **1.2.4 Cognitive Behaviour Therapy**

Cognitive-behavioural therapy (CBT) is effective in reducing annoyance and distress associated with tinnitus, depression and anxiety, results in improved quality of life and results from a meta-analysis suggest improvements can be maintained over time (Tunkel et al., 2014). CBT achieves this through adaptation of maladaptive cognitive, emotional, and behavioural responses to tinnitus via cognitive restructuring and behavioural modification. Participants learn that the way that they think, results in a particular emotional reaction and that their thoughts influence behaviour, i.e. the way tinnitus is perceived (Cima et al., 2012; Langguth et al., 2013; Tyler, 2006).

CBT is a common approach, a survey of English health professionals involved in tinnitus management found 46% of respondents offered CBT (D. Hoare et al., 2012). The main components of CBT includes psychoeducation, relaxation training, mindfulness-based training, attention-control techniques, imagery training, and exposure to difficult situations which are collectively used to modify maladaptive behaviour (Cima et al., 2012; Langguth et al., 2013; Tyler, 2006). Therapy is delivered by a clinical psychologist or psychiatrist (Hoare et al., 2011) and can take between 7 and 22 hours in total, over a period of 6 to 15 weeks (Hesser, Weise, Westin, & Andersson, 2011). CBT is effective as a software package (Hoare et al., 2011) as well as an online program, called internet-based cognitive behavioural therapy intervention (iCBT). Studies have found iCBT to be equally as effective compared to group CBT (Kaldo, Cars, Rahnert, Larsen, & Andersson, 2007) and individual face to face

treatment (Beukes, Andersson, Allen, Manchaiah, & Baguley, 2018) in reducing tinnitus stress and related difficulties.

However, while CBT has by far the strongest evidence base for tinnitus management (Andersson & Lyttkens, 1999; Hesser et al., 2011; Martinez-Devesa, Perera, Theodoulou, & Waddell, 2010) and the AAO-HNSF recommended CBT to patients with persistent, bothersome tinnitus with a Grade A evidence base, its highest recommendation (Tunkel et al., 2014) access to CBT is limited due to a shortage of trained clinicians (Beukes et al., 2018). Hoare et al. (2015) reported in their 2014 survey of tinnitus service provision in the UK that less than half of audiology departments in the UK have a member with CBT training, and specifically none in Northern Ireland. Further development of iCBT protocols may lead to wider accessibility to this highly effective method of tinnitus management.

### **1.3 Health Education**

Regardless of which management approach is applied, communication about the pathology and management of tinnitus provides the individual with information, makes them feel less victimized and puts them in a better position to effectively manage their tinnitus (Tyler, 2006). However, historically, health professionals have found providing effective communication to patients intrinsically problematic (Houts, Doak, Doak, & Loscalzo, 2006).

The difficulty for health professionals trying to communicate health information is that most patients are unfamiliar with the medical terminology used. Health professionals want to communicate clearly with their patients and often this is achieved by using technical, medical terminology that allows them to be precise and specific. The difficulty arises as this medical jargon is frequently not translated because there is no layperson equivalent, and therefore

translation would not be precise or specific. This makes effective communication especially difficult for patients and families with lower literacy skills or those trying to cope with the symptoms and/or emotions of what they are experiencing, while simultaneously trying to use the context of what is being said to understand the meaning behind the medical jargon (Houts et al., 2006).

For these reasons, it is especially important there is a focus on the relationship between hearing specialists and their clients, the way tinnitus is discussed and the language that is used. It is equally as important to place a focus on health literacy and the accessibility of the written information professionals provide (or direct patients to). It is vital these materials are accessible as they help individuals and families to remember and contextualise what they hear, ensuring there is not complete reliance on verbal information (Houts et al., 2006).

### **1.3.1 Patient Centred Care in Audiology**

Facilitating effective professional and patient communication, is a key concept of patient centred care along with patients shifting from passive to active consumers of health information and engaging collaboratively in decisions about their health and wellbeing (Eysenbach & Jadad, 2001; Goodyear-Smith & Buetow, 2001). This change has occurred in light of social movements, like socialism and feminism, and the times we live in with huge technological development and increased autonomy over our lives.

The internet has enabled easy access to information, and debunked the health professional as the sole gatekeeper of health information (McMullan, 2006). Many patients now feel they are able to find information about their health conditions and treatments independently. In some cases they may also have superior internet skills than the health professionals they are dealing

with (Anderson, 2004). Because of the combination of these factors, patients want to be fully informed and part of the decision making process (Goodyear-Smith & Buetow, 2001; McMullan, 2006). Additionally and importantly, evidence based practice shows that patient outcomes are better when value is placed on patient input (Goodyear-Smith & Buetow, 2001).

Work has begun to define what patient centred care looks like specific to rehabilitative audiology (Grenness, Hickson, Laplante-Lévesque, & Davidson, 2014). It is clear that at the core of patient centred care is the individual. This places their occupation, identity, beliefs and values at the centre of all decisions when deciding on the best course of action for treatment or management (Goodyear-Smith & Buetow, 2001).

Equally important is consideration of their motivation, readiness for treatment and the influence of their emotions on these factors (Grenness et al., 2014; Laplante-Lévesque, Hickson, & Worrall, 2010). Emotion, rather than cognition, is understood to be a building block of health beliefs that underpins an individual's health behaviours and decisions. Application of patient centred care in audiology would result in an understanding of the client's perception of their hearing disability and that the beliefs they hold that arise from the experience of those around them and their personal preferences (Laplante-Lévesque et al., 2010).

#### **1.3.1.1 Patient Centred Care in Audiology and Shared Decision Making**

Patient centred care in audiology also involves shared decision with a two-way exchange of information with the patient and the hearing professional working as partners (Eysenbach &



Jadad, 2001). Shared decision making is essential in the management of tinnitus, especially because of its frequent co-occurrence with hearing loss.

As already established, there is no standardised protocol for tinnitus treatment and treatment can be trial and error to see what works for each individual. Additionally, adults with hearing loss treat the management of their hearing as on-going and reversible because it is framed as a slowly degenerating, chronic health condition. In contrast to with people with acute health conditions, people with chronic health conditions frequently revisit their decisions according to the stability or progression of their condition and its consequences (Montori et al., 2006).

This has clinical relevance as it underlines the need for effective, open and transparent communication. Together hearing specialists, patients and their family and friends must practice effective patient centred care and shared decision making as they may regularly revisit intervention plans and reconsider options dependent on the severity of their tinnitus and the evolution of their hearing impairment (Laplane-Lévesque et al., 2010).

### **1.3.2 Self-Management**

Another by-product of the internet creating easy access to information and individuals' increasing independence from health professionals is self-management. Self-management is defined as "the tasks that individuals must undertake to live with one or more chronic conditions" (Corrigan, Greiner, & Adams, 2004, p. 57) and is made up of five key skills: (1) problem-solving, (2) decision-making, (3) appropriate use of resources to gain knowledge of the condition and/or its management (4) forming a partnership with a health-care provider and engaging in shared decision making; and (5) taking necessary actions such as: addressing risk factors, adopting lifestyles to promote health and accessing support services when

needed (Lawn & Schoo, 2010; National Health Priority Action Council, 2006; Taylor et al., 2014). These skills cumulate in an individual with a long-term or chronic condition having “the confidence to deal with medical management, role management and emotional management of their conditions” (Corrigan et al., 2004, p. 57). Successful self-management is promoted by leading health organisations as an “indispensable component of modern health care” (Taylor et al., 2014, p. 5) and can facilitate acceptance, learning to live well alongside the consequences of their symptoms and improved health outcomes (Coleman & Newton, 2005).

Self-management is the first stage on The GPG tinnitus pathway where the “patient with tinnitus, with or without hearing difficulties, needs to take some responsibility for their tinnitus and hearing condition” by increasing their own knowledge of their condition e.g. by consulting the internet to understand the “first line of support” such as seeing a GP, or learning about lifestyle changes to help manage tinnitus (Department of Health, 2009, p. 17). However while self-management is an inevitable component of modern health care and is associated with improved health outcomes, Manchaiah, Ratinaud, and Andersson (2018) have commented that when individuals self-manage a large contributing factor as to how effectively they self-manage, is attributed to the information they obtain through various sources (such as online content, the news media, health professionals and friends and family). Therefore it is important to consider how these sources facilitate or inhibit self-management in regards to their consideration of the health literacy of their audience.

### **1.3.3 Health Literacy**

Literacy is commonly defined as a person’s ability to read basic text and write a simple statement. Literacy skill is crucial as reading and writing plays a large part in determining the

participation (both socially and economically) that an individual has in their community and the amount of control they have over day-to-day events (Nutbeam, 2008).

Low literacy skills are common and have been an issue for some time. In 1992 the National Adult Literacy Survey classified literacy into levels, 1 through to 5, each level increasing in proficiency. The survey found approximately 50% of Americans surveyed (16 years and older) had the lowest levels of literacy skills (levels 1 and 2). These results suggested that a significant portion of respondents were illiterate or only able to locate one piece of information from a simple, short piece of text and another significant portion of respondents were only able to locate information in moderately complicated text, but had difficulty finding information in text that had distracting information and in complex formats in which the information is presented (Kirsch, 1993).

It is easy to follow that an individual's ability to read and understand written information has clear implications for how effectively they may be able to use health information (Laplante-Lévesque, Brännström, Andersson, & Lunner, 2012). Literacy specific to health information is called health literacy, and is defined by The United States Institute of Medicine as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (Nutbeam, 2008, p. 2073). According to the World Health Organization (2016) an individual's health literacy is dependent on many factors. Some of these factors are related to the individual (e.g., the person's knowledge of the health topic, the person's culture, the person's attitude and motivation). Some of these factors are related to the healthcare system itself (e.g., how easily information is accessible, how easy the healthcare system is to navigate).

Health literacy is often in line with “social gradient” and will most likely reinforce existing socioeconomic inequalities and lead to poorer health outcomes (The World Health Organisation, 2013). Low health literacy is associated with reduced “participation in health promotion and disease detection activities, riskier health choices (such as higher smoking rates), more work accidents, diminished management of chronic diseases (such as diabetes, HIV infection and asthma), poor adherence to medication, increased hospitalization and rehospitalization, increased morbidity and premature death” (The World Health Organisation, 2013, p. 7).

Like more general literacy skills, low health literacy skills are common and should be a concern to health practitioners alike (Kutner, Greenburg, Jin, & Paulsen, 2006). The 2003 National Assessment of Adult Literacy included health literacy assessment information. The survey assessed three areas of health literacy. The knowledge and skills needed to search, comprehend, and use information in (1) sentences or paragraphs (information like what might be in health promotion magazines or a pamphlets in a doctor’s office), (2) from non-continuous texts in various formats (skills that may be required to fill in a prescription) and (3), the knowledge and skills needed to identify and carry out arithmetic sums using numbers from printed materials (a skill that may be required to understand and a health insurance form). These health literacy tasks represented a selection of literacy activities adults likely to face in their daily lives. The survey found the majority of American adults have intermediate health literacy skills meaning they can understand, summarise and make inferences in moderately dense text, make simple inferences from dense text and use slightly complex arithmetic skills. However, 22% had Basic health literacy, indicating skill to perform simple and everyday activities and 14% had Below Basic health literacy. These simple skill sets

mean, around a third of Americans can only identify information if it is short, simple, explicit, and preferably familiar.

The health literacy of patients seeking treatment for hearing issues is unknown, however the overall poor picture of health literacy likely sets the scene for this population (McCormack et al., 2010). Many of the factors related to health literacy can be difficult to change; however, aspects that are relatively easily addressed are those relating to the accessibility of health materials that individuals use in order to learn more about a health condition and/or make decisions about management or treatment. In order to promote patient centred care, the challenge for health professionals is to present information in an accessible manner so that individuals can effectively manage their health care (Doak et al., 1996).

## **1.4 Sources of Health Information**

### **1.4.1 General Practitioner**

Traditionally GPs have been a key provider of health information and services for individuals with health issues. They have specialised knowledge and power to effectively advocate for their patients' well-being (Goodyear-Smith & Buetow, 2001). In acknowledgment of this, a high level of trust is placed on in the support and information provided by GPs (Hesse, Nelson, Kreps, & et al., 2005).

### **1.4.2 Printed Health Information**

Printed health information in the form of brochures, flyers or booklets, is a traditional method of dispensing health information. Health professionals use resources like brochures as teaching tools to create public aware of services, to encourage prospective patients to engage

with health services and to provide initial background information or reinforce information they may have given verbally (Gal & Prigat, 2004; Shieh & Hosei, 2008).

### **1.4.3 Family and Friends**

Individuals with health concerns often seek health information from family and friends. A 2008 study found that 29% of adults referenced friends, family and/or co-workers as a source of health or wellness information (Elkin, 2008). Additionally, once individuals find health information online, most will talk it over with friends, family or members of their wider circle (Susannah Fox & Purcell, 2010). To add to that, approximately half of the searches for health information are on behalf of someone else. This suggests the internet has become a platform for individuals to not only access and but also exchange and trade health information and a patient may present to a health professional with something they did not find themselves (Susannah Fox & Duggan, 2013; Hesse et al., 2005).

### **1.4.4 News Media**

For many individuals, the news media is a key resource used to develop and inform their world view and therefore plays a key role in determining the trajectory of individuals' thoughts and opinions (McCombs & Shaw, 1972). It follows that the news media may be an influential source for tinnitus information. Manchaiah et al. (2018) reported on the representation of tinnitus in the US newspaper media and found a focus on two main areas: (1) disease specific information (symptoms, self-management and social support) and (2) developments in treatments for tinnitus. The first focus was a positive finding because it is important to provide information on these three points in order for an individual to solve their immediate health problem. The second point may be of concern because the researchers noted that the majority of media attention for tinnitus treatments has not focused where the evidence base is highest, for example cognitive behavioural therapy. Media attention has

reported on innovations such as brain stimulation, a management strategy not recommended in the GPG or by the AAO-HNSF. This may be of some concern because this arguably very influential source of tinnitus information has, according to this study, failed to publicise and promote evidence based management options.

#### **1.4.5 The Internet**

In the US, studies investigating the internet as a source of health information have reported high rates of use with 56% - 79% of individuals who use the internet using it to seek health information (Hesse et al., 2005; Ybarra & Suman, 2006). Additionally round 46% of individuals report using the internet as their first source of information, compared to around 10% seeking a consultation with their GP (Hesse et al., 2005). A 2003 survey about online health information commissioned by the European Union (EU) found roughly a quarter of Europeans (23%) used the internet to access health information while 41.5% of individuals in the EU thought the internet was a good way of accessing health information (European Commission, 2003).

Individuals seeking out health information access it through a variety of ways. Most individuals use a generic online search engine. For instance, 77% of individuals start their search using the search engines Google, Bing or Yahoo. A smaller portion (13%) start at a site like WebMD that specializes in health information. A very low portion of users begin at Wikipedia (2%) or Facebook (1%) (Susannah Fox & Duggan, 2013).

Individuals primarily use the internet for general reading on a health topic or for condition specific information on symptoms or treatment (Shuyler & Knight, 2003; Ybarra & Suman, 2006). Ybarra and Suman (2006) examined the characteristics associated with individuals

seeking health information online and reported that 2 out of 5 people use the internet to try to diagnose a health issue and 1 out of 3 people attempt to treat a health problem with information they find online. Almost half of the Internet users claim they have used the Internet to decide whether they need to see a doctor. As a flow on to this, 1 out of 4 of respondents said they also use the Internet to prepare for or follow up from a doctor's appointment, and 1 out of 3 of respondents said they that brought the information with them to their appointment to suggest information to their GP or query information they found (Ybarra & Suman, 2006).

The Health on the Net Foundation found in a survey of users (mainly from North America) of the internet for health information, 75% of respondents were accessing information directed at health professionals. They felt information directed at “consumers” was too basic and the level of depth covered was insufficient (C. Boyer, Provost, & Baujard, 2002). This highlights an important factor, that the intended reader of information on the internet it not always the end recipient which may cause misunderstandings and confusion. However, respondents reported they were proactively addressing points of uncertainty, with 86% performing alternative searches to clarify information and similar to the 2006 Ybarra and Suman study, 32% asking their GP if they did not understand information online (C. Boyer et al., 2002).

Use of the internet as a source of information may also be specific to the perceived number of treatment options, risk or sense of crisis associated with the health issue or decision. People seek more information from a variety of sources on and off-line when they perceive a potential treatment outcome decision to be both risky and with arguments for and against different treatment (Couper et al., 2010; Wallhagen, 2009). Fox and Duggan (2013) investigated individuals' search and information assessment strategies in times of crisis.



Respondents were asked about the last time they had a serious health issue and what sources they sought help from, on and off-line. The majority of respondents did not list the internet as a source of information: 70% respondents sought information, care, or support from a doctor or other health care professional, 60% respondents sought information or support from friends and family and 24% of respondents sought information or support from others who have the same health condition (Susannah Fox & Duggan, 2013).

The differing use of the internet in times of serious health concerns and a sense of crisis may indicate the importance or trust users place in the internet as a source of health information. Ybarra and Suman (2006) and Andreassen et al. (2007) investigated how important users considered the internet to be as a source of health information found similar results. Both studies reported 40% of respondents consider it an important source of information. However, approximately double this number felt face-to-face contact with health professionals, like seeing a GP, far more important, (79% and 82%, respectively).

Trust of health information is strongly associated with education and age. People with higher levels of education, high school or further, are more trusting of the internet (and magazines and newspapers) than people with less than a high school education. Adults between 18 – 34 years of age are 10 times more likely, and adults ages 35 – 64 years of age are 5 times more likely to report trusting information on the internet “a lot” or “some”, than people 65 years of age and older. This feeling of trust translates to sources different age groups use as their first resort for information. Adults aged 18 – 34 years have been found to be almost 9 times more likely to go to the internet first before going to see a health provider. Whereas in the 65 years and older age group, the portion was split almost evenly (21.4% vs 20.9%) on which source they would seek information from first (Hesse et al., 2005).

It is clear the Internet is not a replacement for traditional services but there is interaction between these sources of information. It seems that the internet may serve two main purposes for health information. First, individuals are using the internet as a complimentary resource or for a second opinion, especially when the health concern is considered non-life threatening. Indeed, 78% of people who used the Internet for health information reported feeling better about information they had received from their healthcare provider because of what they found online (Ybarra & Suman, 2006). Second, it seems an internet search on a health condition may act as a quasi-screen to see if a trip to the GP or another health professional is justified, according to what information is found. This makes it a very useful tool as health information online is very accessible and compared to a consultation with a health professional, relatively inexpensive to access, and in some cases free.

#### **1.4.5.1 Social Media**

In 2017 Elkarim et al. estimated that 65% of individuals globally were active on social media and as individuals look further afield than health professionals for health information and advice, social media sites like Facebook and YouTube are being utilised as health information resources. These social media sites are ranked as the first (Elkarim et al., 2017) and second (Alexa, 2018) most popular social media networks globally. Through social media individuals are able to access professional knowledge, emotional support and advice (Overberg et al., 2010) find, interact with and utilise user-generated content (as opposed to content created and controlled by the information provider) as well as access disease-specific patient networks (Susannah Fox & Purcell, 2010).

Given what is known about individuals' tendency towards collaborative decision making in regards to health concerns perhaps it is not surprising social media has evolved in this way: one third of individuals reference friends, family and/or co-workers as a source of health or wellness information (Elkin); most individual's discuss information they find online with members of their family or friends (Susannah Fox & Purcell, 2010); and in cases of serious health concerns a quarter of individuals surveyed by Fox and Duggan (2013) sought information from someone who had the same health condition.

In regards to use of social media, Hawn (2009) states that for those with chronic diseases (like tinnitus) social media is a communication tool essential for both management and empowerment. In 2010 Fox and Purcell reported blogging and participation in online health discussions as key activities among individuals living with chronic disease, therefore it is likely individuals with tinnitus are utilising social media as a source of health information by sharing what they know and learning from their peers. Sarasohn-Kahn (2008, pp. 5-6) has found "when patients managing the same chronic condition share observations with each other, their collective wisdom can yield clinical insights well beyond the understanding of any single patient or physician". She states that when patients managing the same chronic condition share observations with each other this improves their chances of discovering new information, and the issue of location is made redundant. Whereas before due to their geographic community individuals may have missed out discussing their condition with someone in a similar position, the global nature of the internet and social media enables communication with individuals world-wide (Sarasohn-Kahn, 2008).

#### **1.4.5.1.1 YouTube**

A systematic review of healthcare information on YouTube published in 2015 found YouTube is increasingly being used to share and access health information (Madathil, Rivera-Rodriguez, Greenstein, & Gramopadhye, 2015). Basch et al. (2018) examined the 100 most widely viewed videos on YouTube and found the majority (3/4) of the content was individual experience videos and a quarter of content was uploaded by professionals. It is this smaller chunk of content uploaded by professionals that, of the 100 most widely viewed videos had the most views (Basch et al., 2018) and is also the most likely to provide high quality, trustworthy information (Madathil et al., 2015).

In regards to the content of these 100 most widely viewed videos, Deshpande, Deshpande, and O'Briens' 2018 study investigated the prevalence of tinnitus related information on social media platforms Twitter, Youtube and Facebook. They analysed videos according to their relevance, view count and rating and found 36% of the first 100 videos sorted for relevance was videos playing masking sounds such as white noise and running water. Therefore it is possible that these videos may facilitate effective self-management (Tunkel et al., 2014). The authors noted that it is likely these videos have a high view count because individuals viewed them hoping to encounter new information to be cured of their tinnitus, however they also were found to have a significantly greater number of likes. The high number of likes signifies that many individuals have found the videos helpful, and by liking it are hoping to promote its viewing to others. This is indicative of how social media in a health context works, peers supporting peers with a "do-it-yourself" (with the help of others) approach to management.

#### **1.4.5.1.2 Facebook**

Deshpande, Deshpande, and O'Brien (2018) found the highest amount of tinnitus related activity to be on Facebook when compared with YouTube and Twitter, another popular social media site. Individuals may follow a page (this may be the public profile of an entity, business or an organisation) or be a member of a group (an assembly of individuals interested in discussing a specific topic). A large portion of tinnitus related discussion on Facebook (43.3%) relates to information about diagnosis and symptoms, information that individuals require to effectively self-manage. Uses also extend to social support, learning to cope and accessing tinnitus related research. Facebook groups, more so than pages, offer individuals with tinnitus a space to share stories and advice (Manchaiah et al., 2018).

#### **1.4.5.2 Misinformation**

It is clear that online content (webpages and social media) has benefits for self-management, empowerment, support and fostering a sense of community however misinformation exists within this information. The nature of user-generated content on social media is changing the way people become informed, interpret facts, and form their opinions (J. Brown, Broderick, & Lee, 2007). Within Facebook pages, groups and YouTube channels, like-minded individuals are able to connect with each other and process information via a shared system of meaning (Bessi et al., 2015). However Del Vicario et al. (2016) commented that interpretation of information that is learnt on social media is often 'content-selective' and biased towards self-confirmation, as opposed to seeking out evidence based practice. Basch et al. (2018) examined the 100 most widely viewed videos on YouTube. They found the majority of the content was individual experience videos, content that is evidently being viewed by many individuals however that lacks formal fact checking and editorial review. Content may be easily altered, plagiarized or misrepresented and Bessi warns that on a large

scale, misinformation can lead to behaviours strongly divergent from recommended practices (2017). Misinformation accounts for nearly a third of YouTube content (if sorting for relevance) and nearly half of Facebook content (42.7% of Facebook pages and 44.4% of Facebook groups). Therefore a potential risk when using social media as a source of health information is that users unknowingly accept misinformation from their peers, on the basis of their face validity without seeking evidence based advice (Deshpande et al., 2018). Deshpande et al. (2018, p. 10) recommends that health professionals educate themselves on “the current climate of social media’s portrayal of tinnitus” so they are able to provide more accurate information and improved health outcomes.

It may be that some misinformation is due to ignorance or a biased exposure of content, however some misinformation online within the provision of tinnitus management is malicious. Deshpande et al. (2018, p. 9) discuss websites selling “miracle drugs that are clearly unscientific” therefore it is clear that hearing professionals must promote evidenced based information to minimise the impact of this widespread misinformation.

#### **1.4.6 The Vulnerability of People with Tinnitus**

Given the unmediated access to online tinnitus information that individuals now experience, and the wide availability of misinformation, some researchers have found individuals with tinnitus, especially bothersome tinnitus, to be a vulnerable subset.

It is crucial health professionals inform their patients there is no established cure for tinnitus (Beck, 2017; Blakley, 2016; Tunkel et al., 2014). However Tunkel et al. (2014) discussed that while many individuals seek help for tinnitus they are often told by health professionals that nothing can be done to help them. This is misinformation in itself, and may be harmful, because effective, evidence based management strategies do exist that may lead to improved

perception of tinnitus and associated factors, such as quality of life, depression and anxiety. However keeping in mind tinnitus is sometimes described as a chronic health condition, Tunkel et al. explains “some patients are desperate” and coupled with this “some not well-informed; often, such patients will seek any kind of treatment offer that has the appearance of legitimacy” (2014). Additionally, a study investigating the representation of tinnitus in the US media found the information promoted in the media focuses on a promotion of emerging experimental tinnitus treatments, as opposed to well established, evidenced based treatments, like CBT (Manchaiah et al., 2018). Therefore it cannot be expected that individuals will encounter effective, evidence based management techniques through the mainstream media either, and the media may even be priming individuals towards being more inclined to investigating experimental treatments.

Beck (2017) and Blakley (2016) both discuss the vast amount of fake tinnitus cures available over the internet. These “miracle drugs” have been previously discussed, and may come in the form of pills, lotions or potions, none of which are FDA-approved or evidence based cures (Beck, 2017). However for someone who has been told there is no cure for there tinnitus and is desperate for help, the legitimacy of some websites selling the miracle cure may be hard to discern as Blakely notes some scams are blatant or even humorous while others are subtle (2016).

This vulnerability coupled with a trend towards less orthodox treatment in lieu of standard practice advise is not unique to those living with tinnitus, but a wider trend acknowledged within those living with a chronic disease. 38% of internet users with a chronic disease reported looking online for alternative treatments, and 22% report looking online for experimental treatments (Susannah Fox & Purcell, 2010). Within tinnitus management

however this trend may be concerning. A large subset of individuals and their families use the internet as their first port of call for health information and may be active on social media and therefore may be susceptible to misinformation. In addition to this, only a small number of individuals seek professional help for their tinnitus (1-2%) therefore this potentially harmful misinformation and exploitation of a vulnerable population may continue, unmediated by health professionals.

## **1.5 Online Health Information**

### **1.5.1 Internet Penetration for Health Information Online**

Internet use has grown steadily and achieved a high degree of penetration, especially in high-income countries. A 1997 federal scientific survey estimated internet penetration in America to be 22% of individuals 3 years and older, by 2001 this figure had grown to 53.9% (Victory & Cooper, 2002). Since then internet availability and accessibility has increased due to technological advances and lower-cost access to broadband internet (Tennant et al., 2015). In 2010, the U.S Census Bureau reported that 75% of Americans lived in a household with internet access, and that 65% of the population used the internet at home and 38% used the internet outside of home (U.S. Census Bureau, 2012)

In 2017, the global internet user penetration rate was estimated at 49.7%. Internet penetration was higher in high-income countries with regional estimates including 88.1% of North America and 68.1% of Oceania/Australia compared to 28.3% of Africa, 45.2% of Asia and 56.7% of the Middle East (Internet World Stats, 2017).

Adults 18 – 29 years of age are the largest consumer group of health information online, especially females, those with higher education (college or further), and those who live in



households earning \$75,000 or more, or not working at all (i.e., students) (Andreassen et al., 2007; Susannah Fox & Duggan, 2013). Individuals who tend to use the internet to find health information the least, are people of Black-non Hispanic and Hispanic ethnicity, aged 65 years or older, did not finish high school and earn less than \$30,000 a year (Susannah Fox & Duggan, 2013). There may be a generational component to the concentration of younger users compared to older users. Younger adults may be more internet savvy or the health information they seek is novel due to less life experience. Whereas individuals 65 years or older may have personal experience to guide them that younger people lack, or a combination of these factors (Couper et al., 2010).

However, it is also clear that Socio-economic status (SES) is a strong predictor of internet use for health information (Wangberg et al., 2007). The cause of the disparity of access is likely multi-pronged. SES and health outcomes are strongly correlated, as are SES and literacy outcomes (Graham, 2002; The World Health Organisation, 2013). Additionally, literacy, especially health literacy, is likely to determine use of the internet for health information (McCray, 2005; Nutbeam, 2000).

### **1.5.2 Health Informatics**

In light of increasing access to online health information and individuals' participation in health care decisions a need has arisen for health informatics, an interdisciplinary field interested in the use of IT in health care (Eysenbach & Jadad, 2001; Nelson & Staggers, 2016).

Health informatics involves analysis and integration of consumer preferences and information needs in the areas of health promotion, research and clinical practice and there is a specific focus on the effectiveness and efficiency of online information provided for

consumers. By focusing on consumer preferences and needs when creating online health information, users should be able to judge the pros and cons of all possible courses of action with reference to their values, beliefs, preferences and personal circumstances (socioeconomic and health) in the most effective and efficient manner (Eysenbach & Jadad, 2001).

In reality, online health information has not yet reached this gold standard. In the field of audiology it is largely unknown whether the information informs or misinforms adults with hearing impairment and their significant others (Laplane-Lévesque et al., 2012). Those who are most likely to have health problems and are least likely to have access to the Internet or have the skills to use it. However, it is these populations especially that may benefit greatly from a focus on health informatics (Eng et al., 1998).

### **1.5.3 eHealth Literacy**

It is clear that access to online health information cannot promote improved health outcomes if users lack the unique skill set and literacy, called eHealth literacy, to effectively use online information (McCormack et al., 2010; Norman & Skinner, 2006). eHealth literacy is the ability to seek, find, understand, and appraise health information from electronic resources and apply that knowledge to solving a health problem or making a health-related decision (Norman & Skinner, 2006). It combines six core literacies: (1) traditional literacy (the ability to read text, understand written passages, and speak and write a language), (2) health literacy, (3) information literacy (knowing how to collect information, develop research strategies and filter results), (4) scientific literacy (how to understand the nature, aims, methods, application, limitations of health research), (5) media literacy (an ability to critically appraise media content), and (6) computer literacy (the ability to use computers to solve problems) (Norman & Skinner, 2006; Tennant et al., 2015).

Low eHealth literacy is a major barrier to locating, evaluating and using online health information (Car, Lang, Colledge, Ung, & Majeed, 2011). Interventions targeting individuals' eHealth skills aim to address these barriers. They can include training on technical skills such as how to use an internet browser and effective search skills like how to use a search engine. Individuals may learn about particular websites that require less advanced literacy skills or condition specific sites or high-quality sites like MedlinePlus. They may also learn evaluation skills to assess the quality of a website, or how to use and apply information to make health decisions. (Car et al., 2011).

These interventions are thought to directly enhance internet skills and self-efficacy leading to increased health knowledge, improved information handling and improved health behaviours (Car et al., 2011). A 2011 Cochrane Review on the effects of interventions for enhancing consumers' online health literacy found that high quality research is lacking in this area and limited conclusions can be drawn about the efficacy of treatment. There was suggestion that that these interventions may increase the likelihood of individuals using the internet to seek out health information, but not an increase in individuals' eHealth literacy skills (Car et al., 2011).

## **1.6 Content, Quality, Readability and Suitability of Online Health Information**

### **1.6.1 Content of Health information**

Given that online health information can be variable, misleading or incorrect, this indicates a need to evaluate the standard of this information (Lawrentschuk, Abouassaly, Hackett, Groll, & Fleshner, 2009). This is a measure called content, or , accuracy assessment and aims to insure health information is current, accurate, evidence-based and unambiguous, with the end result being that individuals have the most valid, reliable and effective health information at

their disposal (Lawrentschuk et al., 2009). Hendrick et al. (2012) stated that this measure is particularly important for effective self-management.

Presently there is no standardised measure to evaluate the content or accuracy of online health information, however it is standard practice among studies that have evaluated this measure for researchers to develop an original measure that checks the inclusion of disease specific keywords or phrases relevant to symptom, diagnosis and treatment or management information (Ahmed, Sullivan, Schneiders, & McCrory, 2012; Alsaiani, Joury, Aljuaid, Wazzan, & Pines, 2017; Fackrell et al., 2012; Hendrick et al., 2012). This information is typically identified using an industry gold-standard set of evidence based practice guidelines identified by the authors (Ahmed et al., 2012). So far several condition specific instruments have been created to assess brain injury and concussion information (Ahmed et al., 2012), acute lower back pain (Hendrick et al., 2012) and adult kidney cancer (Alsaiani et al., 2017).

Fackrell, Hoare, Smith, McCormack and Hall (2012) assessed the content of tinnitus information preferred by UK GPs. All terminology relating to primary care in the ‘Suggested components of the Tinnitus network’ section of the GPG was selected as keywords, i.e. for instance some key words included in the management section of the content “check list” as it where included “ear wax removal”, “educate patient”, “sound devices”, “hearing aids” and “self-help groups” and the content assessment noted the mention or omission of the selected keywords and the context in which they are mentioned. This study concluded that all websites lacked information relating to either tinnitus assessment or management options, which finds that none of the websites commonly used by GPs in the UK was promoting a full picture of evidence based practice for assessment and management. To date no research has assessed the content or accuracy of online tinnitus information directed at consumers, and

this is not an area of assessment included in this current study. However, this research would be valuable information given individuals' reliance on accurate information to self-manage tinnitus and to quantify the concern around tinnitus misinformation.

### **1.6.2 Quality of Health Information**

A distinctive feature of the internet is that almost anyone can be an author of a webpage. This has prompted concerns about the quality of online health information. Unlike newspapers, magazines and television that typically have levels of fact checking and editorial review, there are not the same standards for generating online content. Information may be easily altered, plagiarized, misrepresented, or created anonymously under false pretences (Metzger, 2007; Metzger, Flanagin, Eyal, Lemus, & McCann, 2003). While websites attached to print counterparts will likely have the same standards of quality, Metzger et al. (2003) discussed that the majority of information on the internet is less formal information generated by special interest groups, individuals, and organizations and material for which the level of editorial review is not explicit.

Studies analysing the quality health information online have consistently identified a risk of encountering inaccurate, incomplete or biased information on the internet (Eysenbach, Powell, Kuss, & Sa, 2002). Therefore assessing the quality of online information is important (Boyer, Selby, Scherrer, & Appel, 1998; Metzger et al., 2003). Quality of health information can be assessed in various ways. A systematic review found over 250 instruments for patients to assess the quality of health information (Bernstam, Shelton, Walji, & Meric-Bernstam, 2005). Two measures, the DISCERN tool and the Health on the Net (HON) foundation certification, are commonly used in tandem to assess the quality of health information.

The DISCERN tool is a standardized index and can be used by creators of health materials, health professionals, and consumers to evaluate the quality of written information in helping people make treatment choices (Shepperd, Charnock, & Gann, 1999). It contains 15 quality criteria and an overall quality rating. The first section contains 8 criteria relating to the reliability of the information (e.g., sources of information used and balanced information). The second section contains 7 criteria relating to how well the health information material provides information about treatment choices (e.g., benefits and risks of the treatment options and the effect of treatment options on quality of life).

The DISCERN tool has been used to assess health information materials across a variety of health conditions. Fibromyalgia (a long-term condition characterized by symptoms of widespread muscle and joint pain, stiffness and fatigue) websites were found to be unusable for most people and unlikely to provide necessary or accurate information (Daraz, MacDermid, Wilkins, Gibson, & Shaw, 2011). Chronic pain websites were evaluated to be moderate in quality (Kaicker, Debono, Dang, Buckley, & Thabane, 2010).

Fackrell et al. (2012) found tinnitus information targeted at medical professionals was found incomplete with all sites failing to provide acceptable levels of information on assessment and management. (Fackrell et al., 2012). Similarly, Manchaiah et al. (2017) found quality to be lacking in a review of consumer directed tinnitus information. Serious shortcomings were indicated for ¼ of the articles around support provided for shared decision making, discussing quality of life in relation to treatment and discussing the options and outcomes around no treatment.

Whether a website displays HON certification is the second component of a common quality assessment. This is a voluntary website certification scheme set up by The Health on the Net

foundation. HON certification is an indication that web developers adhere to good practice guidelines and principles and are committed to having good quality information and formatting in their website (Boyer et al., 1998). If the developers agree to the stipulated guidelines and principles they display the HON logo on their website to demonstrate their certification (Laplante-Lévesque et al., 2012).

HON certification among hearing-related websites is low. Laplante-Lévesque et al. (2012) and Manchaiah et al. (2017) reported similar rates of HON certification in their studies 14% and 13.5%, respectively. From within the certified group, websites created by government organisations were far more likely to be certified than commercial or non-profit organisations. HON certification is gaining popularity; however, many developers (and consumers) are likely unaware of the scheme and therefore certification has traditionally been low (Manchaiah et al., 2017).

Given a key component of a patient centred care approach is ensuring that individuals are able to engage in shared decision making, the variability in quality of tinnitus information is concerning. Information about assessment, management, impact on quality of life and support for shared decision making are areas where quality is variable, and yet are critical components in a holistic, collaborative approach to the management of tinnitus.

### **1.6.3 Readability of Health Information**

A major component of health literacy is reading and a common way to check the potential comprehension of a piece of health information is to assess its readability (Atcherson et al., 2014). Readability is the ease with which a person can read and understand written materials (Freda, 2005). Readability can be quantified with a reading grade level (RGL), a rating which

suggests the minimum number of years of schooling (according to the US education system) an individual would need to read the text (Laplante-Lévesque & Thorén, 2015). Readability can also be assessed using a combination of formulas that measure readability based on sentence length, number of syllables in the words, number of words with three or more syllables, and/or number of words in the assessed sentences (Shieh & Hosei, 2008).

Three common formulas are the Flesch Reading Ease Score (FRES), the Flesch-Kincaid Grade Level Formula (F-K) and the Simple Measure of Gobbledygook (SMOG). The FRES estimates readability based on the average number of sentences and syllables per 100 words. Higher scores indicate better readability. The F-K translates the 0 – 100 FRES into an American grade level, estimating the RGL. Lower F-K scores indicate better readability. The SMOG uses the number of polysyllabic words (words with at least three syllables) to calculate an estimated RGL. Lower scores indicate better readability (Laplante-Lévesque et al., 2012) As a general rule of thumb, more than one readability formula should be used to gain a full idea of a text's readability.

In 2003, The National Assessment of Adult Literacy report estimated the average RGL of English speaking adults in the US to be at the 7<sup>th</sup> or 8<sup>th</sup> RGL, meaning the average American adult's reading ability reflects the formal education of a 13-year-old (Kutner et al., 2006). With these statistics in mind, to make health materials accessible for patients across the spectrum of reading ability, researchers recommend that information aimed at the general public should be written at a 5 – 6<sup>th</sup> RGL (Doak et al., 1996; Weiss & Coyne, 1997). Lower levels of health literacy are higher among people with less than a high school education, minorities, people from lower socioeconomic backgrounds and the elderly (Kutner et al., 2006).



Readability of consumer directed information in audiology is too high. Laplante-Lévesque et al. (2012) found readers on average needed at least 11-12 years of education to read and understand information on hearing impairment and treatment. A study reviewed the readability of the American Speech-Language Hearing Association's (ASHA) online content directed at the general public. Of the articles assessed, 85.4% had a RGL of 9 or higher, which is inaccessible for the average reader (Atcherson et al., 2014). Manchaiah et al. (2017) assessed online tinnitus information for readability and quality and found the RGL to be between 10 – 12 on average, approximately double the amount of education the average individual may have had access to.

The practical implications of lower reading skills need to be considered by health professionals involved in the management of tinnitus. This is especially important if they provide patients with, or direct patients towards, written information online. In many cases, the management of tinnitus will be unfamiliar to patients and readers with low literacy skills may take words literally, miss the context or meaning, skip over words and tire quickly (Doak et al., 1996). Therefore if patients are provided with information with a RGL that exceeds their ability, miscommunication and misinformation is likely.

#### **1.6.4 Suitability of Health Information**

In 1991 Meade and Smith suggested developers of health information consider more “human” elements such as motivation, visual attractiveness, interest, and cultural and experiential factors, in addition to the quality and readability of a document. It is these human elements that determine the suitability of a piece of health information. They may enhance or

detract from the reading experience and can influence how much health information a reader absorbs (McCormack et al., 2010; Shieh & Hosei, 2008).

Suitability is a valuable health literacy measure because while low reading and literacy skills are widespread, Doak et al., (1996, p. 2) discussed that “the good news is that the great majority of individuals with poor literacy are deficient in only literacy skills- not intelligence. Individuals can learn nearly any health instruction that is designed and presented in ways suitable for them. Unhappily health information often falls short of being suitable and therefore is not understood and accepted by the reader”.

The suitability of health information can be assessed using a variety of measures, some of which include the Suitability Assessment of Materials (SAM), The Suitability Assessment of Material + Comprehensibility Assessment of Material (SAM + CAM) or the Patient Education Materials Assessment Tool (PEMAT) (Beaunoyer, Arsenault, Lomanowska, & Guitton, 2017; Doak et al., 1996). The focus of this study is the SAM tool which contains 22 items that assess the suitability of health information material. The respondent answers each item by rating the material as not suitable, adequately suitable, or suitable. The items are based on the following factors: (1) content, (2) literacy demand, (3) graphics, (4) layout and typography, (5) learning stimulation and motivation, and (6) cultural appropriateness. While it is a standardised measure, there is some grey area in the interpretation of the criteria and room for human error. This could lead to subjectivity in the rating of materials. The use of a secondary rater may begin to address this; however, bias is probably not entirely eliminated (Weintraub, Maliski, Fink, Choe, & Litwin, 2004).

The score on the SAM is calculated by adding the total points for each item and dividing the sum by the total possible score to derive a percentage score. When an item is considered “not applicable”, it is eliminated from the calculation of the total possible SAM score. Therefore, the percentage scores are based on different denominators calling into question the comparability of the scores. One way to address this would be to group materials with the same items scored together and then compare scores only within groups. The percentage scores are interpreted as: less than 39% is inadequate, 40 to 69% is adequate, and 70% and above is superior.

The content factor of the SAM includes an evaluation of: (a) how well the title, introduction, or graphics clearly state the purpose, (b) how well the main content of the material is application of knowledge or skills aimed at the reader, (c) how well the scope is limited to the essential information directly related to the topic, and (d) a summary of the information. In practical terms the content factor is important especially for readers with low literacy skills because if they do not clearly understand the purpose, they may not pay attention, or they might miss the main points. Additionally, they may have a short attention span and quickly lose attention, so it is very important to solve their immediate health problem and provide only essential information, as opposed to reading a series of medical facts, as this information is of the most value to the patient. Pulling all this information together with a summary is critical as readers may miss the main points on first exposure (Doak et al., 1996).

The literacy demand factor of the SAM includes: (a) an evaluation of the RGL, (b) the writing style (conversational, active voice, simple sentence with little or no embedded information), (c) vocabulary that contains common and explicit words, explanation of technical words with examples, and use of imagery words, (d) provision of context before

presentation of new information, and (e) use of learning aids such as “road signs” that precede topics. In practical terms the literacy factor is important in facilitating comprehension. For those with low literacy skills, a low RGL and simple style of writing will increase comprehension and reading speed. Using common words like doctor instead of physician, and imagery words that the reader can “see” like “a runny nose” instead of “excess mucus” will also increase comprehension as will providing subtitles (road signs) to prepare the reader for the next topic and make the text seem less inundating (Doak et al., 1996).

The graphics factor of the SAM includes an evaluation of: (a) how well the cover image – in this case the images on the homepage of the website – conveys the content or purpose, (b) the appropriateness of the illustrations: adult-like, simple, and familiar to the reader, (c) how well the illustrations present the key information without being distracting, (d) the explanations of the graphics, and (e) the use of captions to introduce and/or explain the graphics. In practical terms the graphics factor assesses how well the graphics facilitate understanding of the text. From the get go, the cover image of a website influences the readers’ attitude and interest in the information therefore it is important it is friendly, attractive and portrays the purpose of the text (Doak et al., 1996). Further to this, combining text with simple pictures can increase reader attention, comprehension, recall and buy-in to the materials message, provided that they understand the elements being reviewed (Houts et al., 2006). It is also important that captions are used to describe what is happening in the picture and should be written at a lower literacy level to help facilitate the understanding of people with lower literacy skills (Houts et al., 2006).

The layout and typography factor of the SAM includes an evaluation of: (a) how well the information is presented, e.g., images are near the text they refer to, use of colour and

spacing, and visual cueing such as arrows or shading, (b) typography such as use of both upper and lower case lettering, sans-serif typeface, use of cueing such as bolding, colour, and size, (c) the use of subheads to “chunk” information. Practically layout has implications for individuals of all literacy levels. When the layout is poor, this makes reading the text difficult for readers (regardless of literacy level) and it can be difficult to know where to focus attention. Additionally, information must be chunked with no more than 5 items under a subheading as this is the limit of how many independent items most individuals can recall. All of these factors are crucial so the key messages of the information are not lost (Doak et al., 1996).

The learning stimulation and motivation factor of the SAM includes an evaluation of: (a) elements of interaction such as problems or questions for reader response, (b) modelling desired behaviour for daily living, and (c) motivation for self-efficacy accomplished by dividing complex topics into smaller units to allow readers an opportunity to experience success during reading. Learning stimulation and motivation is key because this indicates how well the information may facilitate behavioural change and improve health outcomes. Because learning is an active process, including features like question and answer sections are vital to actively involve the reader. This facilitates chemical change in the brain that increases the retention of information. Additionally, if information is presented in a way that seems achievable they are more likely to take the health instructions or suggestions on board (Doak et al., 1996).

Finally, the cultural appropriateness factor of the SAM includes an evaluation of: (a) a match between the material and the culture of the intended audience and (b) images and examples that are culturally appropriate for the intended audience and are presented in a positive way.

This is important because for a health instruction to be accepted, it must present cultural images and examples in realistic and positive ways (Doak et al., 1996). However, cultural appropriateness of a text can be difficult to apply when there are not explicit clues about the intended cultural audience, even if there are cues like pictures and graphics (Weintraub et al., 2004).

In an acknowledgment of the large role RGL plays in how understandable information is, the SAM incorporates RGL into its final mark. However, a SAM rating can fall within an adequate range, despite readability for a text being at a level that only someone with a college degree or higher could understand (as opposed to RGL 6) (McCormack et al., 2010). This is a clear justification for how health materials benefit from a separate analysis of quality, readability and suitability.

Previous analysis of healthcare materials has shown the majority of healthcare information to be written at unsatisfactory suitability level. Nasser, Mullan, and Bajorek (2012) analysed the readability, suitability and quality of online patient information regarding the use of Warfarin. Only half of the 11 websites assessed gained an “adequate” rating, with no websites gaining a “superior” rating. Materials have also displayed some consistency in areas of particular unsuitability, with learning stimulation and motivation, graphics, layout and typography tending to score the lowest across different studies (Caposecco, Hickson, & Meyer, 2014; Hoffman & Reed, 2004; Kang, Fields, Cornett, & Beck, 2005; Nasser et al., 2012).

The only published example of the use of the SAM in audiology is a study by Caposecco, Hickson, and Meyer (2014) who used the SAM to assess hearing aid user guides. The

researchers analysed the content, readability and design of 36 written hearing aid user guides using three readability formulas, and the SAM. They found that the majority of the hearing aid brochures (69%) were “not adequate” while only 31% were found to be “adequate”. They also had a mean overall mean RGL of 9.6, which led the researchers to conclude that the hearing aid brochures were overall not suitable for their target population and were not facilitating positive hearing aid outcomes.

Suitability is a valuable measure because at its root it is an estimate of the extent to which a piece of health information facilitates the reader’s understanding of the information and encourages self-efficacy. The reader’s understanding of the information is important because if the reader cannot understand the piece of information then they likely will not be prompted to change or adapt their behaviours and act in a self-efficacious manner (Doak et al., 1996). Self-efficacy is a vital construct because it partly mediates the connection between health education and health behaviour (Leganger & Kraft, 2003). Importantly for self-management (the first step in tinnitus management according to the GPG (Department of Health, 2009, p. 17)) self-efficacy is the mediator between the acquisition of self-management skills, and the enactment of self-management behaviours (Taylor et al., 2014).

Crucially, the exact point of providing patients with health materials is facilitate behavioural change (Johansson, Salanterä, Katajisto, & Leino-Kilpi, 2004). Factors that help build self-efficacy are an initial feeling that the task is achievable, that the task is broken into smaller subtasks so the individual can experience success along the way, repetition of the task and reward for doing the task (Doak et al., 1996). Encouraging self-efficacy is especially important for individuals with lower literacy skills, who are more likely to come from lower SES backgrounds. These individuals are less likely to take on health information and adapt

their health behaviours. This may be because compared to those from higher SES backgrounds, they are more likely to place higher value on external factors such as faith and chance as important determinants of their own health. Coupled with this, it is likely they are less able to read and understand the material (Chamberlain & O'Neill, 1998; Leganger & Kraft, 2003; Paxton & Sculthorpe, 1999). Therefore, it is vital information is as suitable as possible to best encourage all individuals to be self-efficacious and achieve the best possible health outcomes.

#### **1.6.4.1 Suitability Assessment Measure Limitations**

The SAM has several known limitations, the result of which is culminated in several other modified versions of the SAM, namely the SAM + CAM and the PEMAT. Beaunoyer, Arsenault, Lomanowska, & Guitton (2017) found the following as limitations of the SAM: there is no information available about how the tool was created and its initial psychometric properties or its internal consistency, cultural appropriateness is difficult to evaluate for many health education materials, critical elements of comprehension are omitted (attention-getting features, message tone and framing, use of persuasive appeals, inclusiveness and relevancy, and numeric literacy (Helitzer, Hollis, Cotner, & Oestreicher, 2009)) and there are high levels of rater subjectivity.

The SAM was redesigned in 2009 under the acronym SAM + CAM (Suitability Assessment of Material + Comprehensibility Assessment of Material) (Beaunoyer et al., 2017). With the additional comprehensibility assessment, the SAM + CAM includes assessment numeracy literacy, attention-getting features, message tone and framing, use of persuasive appeals, inclusiveness and relevancy. Omitted from this iteration of the SAM is cultural appropriateness and the instrument contains six categories as follows: content, literacy



demand, numeric literacy, graphics, layout/typography, and learning stimulation/motivation (Helitzer et al., 2009).

The PEMAT is a measure of usability and actionability by assessing the factors content, numerical presentation, language, visual materials, layout, as well as the extent to which the material can be used to take action (Beaunoyer et al., 2017). Understandability is defined as when consumers of diverse backgrounds and varying levels of health literacy can process and explain key messages. Actionability is defined as when consumers of diverse backgrounds and varying levels of health literacy can identify what they can do based on the information presented (Shoemaker, Wolf, & Brach, 2014). It has been found to be internally consistent and reliable (Shoemaker et al., 2014).

Given the alternative suitability measures available, this study choose The SAM (1) because of its lengthily track record as a measure of suitability and the resulting familiarity researchers in the area of suitability and health literacy assessment have with it, and (2) for ease of comparison between other suitability studies that used The SAM, namely Caposecco et al. (2014), Kang et al. (2005), Nasser et al. (2012), Ryan et al. (2014) and Vallance, Taylor, and Lavalley (2008).

### **1.6.5 Website Origin**

It may also be helpful to consider if website origin has some involvement towards the quality, readability and suitability of information. This may serve as a suggestion to practitioners and consumers alike about which type of websites may provide the most effective health information. Websites' origins are typically categorised as either commercial (owned by companies or private practices), non-profit (owned by charitable organisations, non-profit, or

academic institutions), personal (e.g., a blog or forum), or government in origin (Kieran, Skinner, Donnelly, & Smyth, 2010). Some researchers hypothesise that websites from commercial, university, and government origins may be of higher quality than personal webpages or blogs due to higher resources to spend on website development (Manchaiah et al., 2017).

Cheng and Dunn (2015) assessed the readability of the most 12 commonly searched health topics on Google, these topics included heart disease, anxiety, depression, arthritis and dementia. Readability was assessed using the F-K, SMOG and FRES formulas. Significant differences were found for FRES scores. Government webpages were significantly harder to read than non-profit pages. There was no significant difference between government and commercial webpages. (Pletneva, Cruchet, Simonet, Kajiwarra, & Boyer, 2011).

Kieran, Skinner, Donnelly, and Smyth (2010) found commercial webpages had poorer quality of information compared to non-profit webpages. Quality was measured through a novel scoring system called the Tinnitus Information Value that provided marks if information like definition, causes and a discussion around different treatment options were provided.

Laplante-Lévesque et al. (2012) assessed the quality and readability of online information for adults with hearing impairment and their significant others. Webpages were of commercial, non-profit or government origin. Across the board readability was poor. Government organisations were most likely to have HON certification however non-profit organisations were found to be higher quality than commercial or government origin websites.

Manchaiah et al. (2017) reported on website origin in their study on the quality and readability of online information on tinnitus. Websites were broken into five categories, commercial, non-profit, government, personal or university in origin. Government websites were found to be significantly more likely to have HON certification, however there were no significant differences reported in readability or quality in that across the board readability was poor and quality was low, regardless of website origin.

There are some early indications to suggest that non-profit organisations may produce material superior in readability and quality, especially compared to commercial and government origin websites (Cheng & Dunn, 2015; Kieran et al., 2010; Laplante-Lévesque et al., 2012). An outlier to this trend being Manchaiah et al. (2017) who reported no significant differences in quality or readability between different origins. However, studies reporting in this area are limited. So far this analysis has not been incorporated in studies assessing the suitability of health information.

The potential trend towards websites of government origin being of poorer readability and quality is of potential concern as they likely benefit from “corporate credibility” (Goldsmith, Lafferty, & Newell, 2000, p. 43). This is the notion where consumers believe in an organisation’s trustworthiness and expertise based off their awareness of the organisation’s history of experience. A 2010 Health On the Net Survey reported that respondents perceived government websites to be the most reliable and trustworthy, and therefore is likely to be a preferred source of information despite the fact that websites like these may not best cater to their health and eHealth literacy needs (Pletneva et al., 2011).

## **1.7 Tinnitus Information Online**

As discussed, 77% of individuals search for health information online using the search engines Google, Bing or Yahoo (Susannah Fox & Duggan, 2013). A Google search of “tinnitus treatment” provides the searcher with over 11 million results from a variety of private and national health service websites, blogs and forums. However, it is clear that the readability, quality and/or suitability of these articles may be compromised which may jeopardize rather than facilitate good health care provision for individuals with tinnitus (Fackrell et al., 2012).

### **1.7.1 Information for General Practitioners**

Medical information on the internet generally has two audiences, consumers and health professionals, and the target audience is typically clear to the reader (Atcherson et al., 2014). It is important to note the quality, readability and suitability of tinnitus information directed at both audiences, not just the consumer, because as discussed the intended reader of information on the internet is not always the end recipient and a large portion of individuals have reported seeking out information designed for professionals because they believe it to be more comprehensive (C. Boyer et al., 2002).

Fackrell et al. (2012) assessed the quality of websites commonly used by GPs in England. GPs often use automatic index databases like PubMed or Ovid, where information has undergone a stringent peer-review process before being uploaded to these sites (El-Shunnar et al., 2011; Kieran et al., 2010). Interestingly, none of the websites reviewed provided information that was comprehensive. At best, the websites that rated most highly provided either acceptable levels of information on assessment or management, but not both. The researchers of this study recommended that GPs accessing information online extend their

search to more than a single website as a cross check to minimise the risk of having incomplete information.

For consumers, this lack of complete information about the assessment and management of tinnitus is pertinent. When they access information designed for professionals, they are doing so because they expect more comprehensive information than what is designed for consumers. However, they may likely be accessing information that is incomplete and missing detail and may not be facilitating the best possible health outcome.

### **1.7.2 Information for Patients**

For individuals who see their GP about their tinnitus, they will likely be provided with information and reassurance as a first management option and often the information they are directed to is online (El-Shunnar et al., 2011). GPs typically refer patients to a specific tinnitus website as opposed to suggesting individuals' turn to a search engine like Google for information (Fackrell et al., 2012).

However the portion of individuals with tinnitus that seek treatment options from a health care professional like their GP is very small, around 8% (Bartels, Middel, van der Laan, Staal, & Albers, 2008). Therefore, the majority of individuals with tinnitus do not seek advice from their GP and given the high use of the internet for health information, it is likely a large number of people with tinnitus self-manage and turn to the internet for information on the cause of tinnitus, symptoms, diagnosis, and treatment options.

The resources that exist for GPs in terms of experience, knowledge and access to specialised websites do not exist for most individuals with tinnitus. They rely on generic search engines

(Google, Yahoo and Bing) to find information. These search engines recommend websites based off mathematical formulas, typically how many times a site is linked or accessed. This system unfortunately does not ensure the websites identified first have been reviewed or edited to a high standard with facilitating health literacy as a paramount concern (Kieran et al., 2010). In addition to this, studies investigating the quality and readability of online tinnitus information are scarce, while there have yet to be any studies investigating the suitability of online tinnitus information published.

In 2010, Kieran, Skinner, Donnelly, and Smyth identified websites most commonly used by patients seeking information about tinnitus to assess the quality and accountability of these websites. The study assumed that the first 30 search results were the most likely sources for someone seeking information off a search engine like Google to access. Quality was measured through a novel scoring system called the Tinnitus Information Value that provided marks if information like definition, causes and a discussion around different treatment options were provided. Findings were variable (scores ranged from 0 – 10) and on average websites scored 50% indicating for most articles a full picture of both causes, assessment and management was not provided and information was incomplete.

More recently, Manchaiah et al. (2017) assessed the readability and quality of online information relating to tinnitus. Information generally exceeded the recommended 6<sup>th</sup> RGL, most articles required 10 – 12 years of formal education to read. DISCERN ratings for quality of online tinnitus information was variable however on average found most articles had shortcomings in the quality of information provided. Few websites had HON certification.

From the two studies available, quality of online tinnitus information seems to vary greatly. However, consumers will likely find information on tinnitus that is incomplete. Only one study has reported on readability, far exceeding the recommended level. However, it is likely that the readability of online tinnitus information in general follows the trend of other health sectors that readability far exceeds the recommended 5 – 6<sup>th</sup> RGL. Research on the suitability of online tinnitus information is absent at present. This limited research in combination with wider health sector trends suggest that the readability, quality and suitability of online tinnitus information needs to be made far more accessible for people with lower health and eHealth literacy skill.

## **1.8 Study Rationale**

Worldwide many individuals have added the internet to their personal health toolbox to help themselves and whānau better understand their health (Susannah Fox & Duggan, 2013; McMullan, 2006). Therefore because of this high use, it is likely that many of the 10-15% of adults world-wide with tinnitus will seek information about tinnitus online (S. C. Brown, 1990; A. Davis, 1995; Khedr et al., 2010; Lasisi et al., 2010; Michikawa et al., 2010).

The readability and quality of online tinnitus information has previously been reported, with reading levels exceeding the recommended RGL of 5 – 6 (Doak et al., 1996; Weiss & Coyne, 1997) and the quality of information variable with incomplete information about assessment and management (Fackrell et al., 2012; Manchaiah et al., 2017).

To date the suitability of online tinnitus information has not been reported. This is important to judge if the content and design of information is being presented in a way that will best facilitate understanding of tinnitus and encourage behavioural change. The results of this

study may better inform web developers and clinicians of the suitability level of online tinnitus information and encourage development of more suitable materials.

## **1.9 Aim and Hypotheses**

### **1.9.1 Aim**

The aim of this study was to investigate the suitability of English language online tinnitus information, as identified and assessed by Manchaiah et al. (2017).

### **1.9.2 Hypotheses**

The following hypotheses are written in null format.

1. There is no significant difference between the SAM ratings for the websites of different origins.
2. There is no significant relationship between SAM rating and DISCERN rating.
3. There is no significant relationship between SAM rating and mean RGL.

### **1.9.3 Expected Findings**

It is expected that suitability of online tinnitus information will be variable, following a similar trend found in the quality of online tinnitus information. For hypotheses 1, 2 and 3 the following results were expected.

**1. There is no significant difference between the SAM ratings for the websites of different origins:** It was expected that websites of non-profit origin would have significantly higher SAM ratings than websites of commercial or other origin. This was expected because of early indications that non-profit organisations produce material of superior readability and quality, especially compared to commercial and government origin websites (Cheng & Dunn, 2015; Kieran et al., 2010; Laplante-Lévesque et al., 2012). Therefore it was anticipated that



this trend would extend to superior suitability. Manchaiah et al. (2017) is an outlier to this trend.

**2. There is no significant relationship between SAM rating and DISCERN rating:**

A significant relationship was not expected between SAM and DISCERN ratings because of the difference in suitability and quality assessment. A difference in ratings provides justification for how health materials benefit from a separate analysis of quality and suitability.

**3. There is no significant relationship between SAM rating and mean RGL:** A significant negative relationship between SAM ratings and readability was expected based off the findings off the findings of Doak et al. (1996) who created and validated the SAM, who found that if readability is high (difficult) then the overall SAM score is usually low (less suitable).

## **Chapter 2:       Methods**

This chapter will discuss the search and selection strategy for this study, the SAM tool used to assess suitability and data analysis techniques. There was no ethical approval required for this study. The study design was inspired by previously published studies on quality and readability of internet information on speech and hearing disorders (Atcherson et al., 2014; Laplante-Lévesque et al., 2012; Manchaiah et al., 2017).

### **2.1 Search and Selection Strategy**

Materials from the Manchaiah et al. (2017) study were used in this study. Manchaiah et al. asked a group of hearing care professionals ( $n = 6$ ) and a group of adults experiencing tinnitus ( $n = 8$ ) for key words they would use to find online information relating to tinnitus. From that information and information provided by Google Trends ([www.google.com/trends](http://www.google.com/trends)), three key words/phrases (tinnitus, ringing in the ear and buzzing in the ear) were identified to perform an internet search using five country-coded Top-Level Domains (ccTLDs) which can be searched using the English language. These ccTLDs were: Australia, Canada, India, the United Kingdom and United States. This search process resulted in the identification of 134 unique websites.

The researchers obtained information about each website's origin (commercial, government, non-profit, personal, or university), and whether the website had HON certification. They used three formulas to assess the readability of the websites (the FRES, the F-K and the SMOG). Finally, they used the DISCERN and HON certification to assess website quality. The results of the study indicated that on average readers were required to have at least 10 – 12 years of education in order to effectively read the online information. Few websites had HON certification and there was high variability in DISCERN ratings.

## 2.2 Suitability Assessment

The focus of this study is on the suitability of the websites identified and assessed by Manchaiah et al. (2017). The SAM tool was used to assess suitability. Before using the SAM tool to rate the tinnitus websites, the author and a second researcher performed SAM ratings on non-study material. This step was important to improve the inter-rater reliability of the SAM ratings. After reaching satisfactory reliability, the author rated a subset of the 134 unique websites identified in the previous study.

The selection of the websites analysed in this study was based on obtaining an equal sample of websites of different origins. Because the sample size was relatively small for the government, university and personal origins, these were combined into one category labelled “other” in this study. Therefore, all websites are categorised as: commercial (n = 66), non-profit (n = 52), and other (n = 16). A random sample of 15 websites from each origin category were selected for SAM rating.

The author rated 37 of the 45 websites using the SAM tool (Commercial = 14, Non-profit = 11, Other = 12). Of the websites randomly selected from the original Manchaiah et al. (2017) study, 8 could not be rated because at the time of the current study their link was no longer active and therefore the websites could not be accessed.

The second researcher independently rated 21 websites using the SAM tool. The purpose of this secondary rater was to ensure correct and reliable representations of suitability. A random selection of 8 websites from each origin category were intended to be rated by the second researcher however, 3 of these links were no longer active and therefore could not be rated.

### **2.3 Data Analysis**

Data were analysed using the IBM SPSS Statistics 22 software. Assumptions of normality were tested and determined to meet the assumptions of parametric testing. Descriptive statistics was explored and in addition, the following statistics were used: interclass correlation coefficient, analysis of variance (ANOVA) and Pearson's correlation. An alpha level of 0.05 was used to determine significance for all statistical analyses.

## **Chapter 3: Results**

### **3.1 Overview**

The purpose of this study was to investigate the suitability of online tinnitus information identified and assessed for readability and quality by Manchaiah et al. (2017). In addition to this, the study compared the suitability between websites of different origins, the relationship between quality and suitability, and the relationship between suitability and readability. In total 37 webpages were analysed. The results of this study found the suitability of online tinnitus information to be adequate. No website origin was found to be creating content of higher suitability than another, neither was higher suitability found to be positively correlated with quality. Additionally, more suitable webpages were not found to be associated with lower readability.

### **3.2 Inter-rater Reliability**

Inter-rater reliability met the criterion established by Fleiss (1981), specifically that the kappa generated by the intra-class correlation (ICC) must be greater or equal to .75. The ICC average measure was .802,  $p < .001$ . The ICC is a widely used measure of inter-rater reliability for quantitative ratings. Values greater than .75 are taken to represent excellent agreement beyond chance (Fleiss, Levin, & Paik, 2013).

### **3.3 Descriptive Statistics**

Table 1 provides a summary of the descriptive statistics for the suitability, readability and quality of online tinnitus information. Table 2 provides a summary of the origin of these materials.

**Table 1. Descriptive Statistics of the Suitability, Readability and Quality of Online Tinnitus Information**

	<b>N</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Std. Deviation</b>
<b>SAM</b>	37	25%	76%	55%	11%
<b>F-K</b>	37	5.9	16.5	10.4	2.5
<b>SMOG</b>	37	8.6	17.5	12.1	2.2
<b>Mean RGL</b>				11.23	
<b>DISCERN</b>	37	1	5	2.3	1.2

*Note 1: SAM stands for Suitability Assessment of Materials; F-K stands for Flesch-Kincaid Grade Level Formula; SMOG stands for Simple Measure of Gobbledygook; N stands for the number of webpages assessed; Mean RGL stands for mean reading grade level and Std. Deviation stands for standard deviation.*

**Table 2. Descriptive Statistics of the Origin of Online Tinnitus Information**

<b>Origin</b>	<b>N</b>	<b>Mean SAM</b>	<b>Std. Deviation</b>
<b>Commercial</b>	14	.56	.11
<b>Non-profit</b>	11	.54	.14
<b>Other</b>	12	.55	.09
<b>Total</b>	37	.55	.11

*Note 2: N stands for the number of webpages assessed; Mean SAM stands for mean SAM score and Std. Deviation stands for standard deviation.*

The suitability of online tinnitus information was analysed using the SAM. Table 3 provides a summary of the frequency of SAM scores (not suitable, adequate or superior, from most unsuitable to most suitable) by item for the 37 materials assessed.

**Table 3. Summary of Frequency of SAM Scores by Item (N=37) (Doak et al., 1996)**

<b>SAM Item</b>	<b>Not suitable Score of 0 <i>n</i> (%)</b>	<b>Adequate Score of 1 <i>n</i> (%)</b>	<b>Superior Score of 2 <i>n</i> (%)</b>
<b>Content</b>			
Purpose is evident		17 (45.9%)	20 (54.1%)
Content about behaviours	16 (43.2%)	17 (45.9%)	4 (10.8%)
Summary or review included	36 (97.3%)	1 (2.7%)	
<b>Literacy demand</b>			
Writing style, active voice	2 (5.4%)	6 (16.2%)	29 (78.4%)
Context is given first		1 (2.7%)	36 (97.3%)
Vocabulary	9 (24.3%)	18 (48.6%)	10 (27%)
Advance organisers	5 (13.5%)	2 (5.4%)	30 (81.1%)
<b>Graphics</b>			
Cover of graphic shows purpose	7 (18.9%)	28 (75.7%)	2 (5.4%)
Type of illustration	9 (40.9%)	4 (18.2%)	9 (40.9%)
Relevance of illustrations	20 (54.1%)	17 (45.9%)	
Graphics explained	2 (50%)	1 (25%)	1(25%)
Captions used	10 (55.6%)	6 (33.3%)	2 (11.1%)
<b>Layout and typography</b>			

Typography			37 (100%)
Layout factors	6 (16.2%)	23 (62.2%)	8 (21.6%)
Subheadings	15 (40.5%)	9 (24.3%)	13 (35.1%)
('chunking' used)			
<b>Learning,</b>			
<b>stimulation and</b>			
<b>motivation</b>			
Interaction used	33(89.2%)	3 (8.1%)	1 (2.7%)
Behaviours are	9 (24.3%)	10 (27%)	18 (48.6%)
modelled and are			
specific			
Motivation/self-	5 (13.5%)	13 (35.1%)	19 (51.4%)
efficacy			
<b>Cultural</b>			
<b>appropriateness</b>			
Cultural images and	11 (55%)	7 (35%)	2 (10%)
examples			

*Note 3: N stands for the number of webpages that received scores of 0, 1 or 2, respectively. 15 materials did not include illustrations, 28 did not include graphics and for 19 materials captions were not required (in absence of supporting illustrations and/or graphics). 17 materials had no cultural involvement. Percentages were adjusted for non-applicable factors.*

Table 4 shows that the majority of materials assessed were rated to be adequate for suitability.



**Table 4. Overall SAM Ratings for the Suitability of Online Tinnitus Information (N= 37)**

SAM Rating	Inadequate <i>n</i> (%)	Adequate <i>n</i> (%)	Superior <i>n</i> (%)
	2 (5.4%)	33(89.2%)	2 (5.4%)

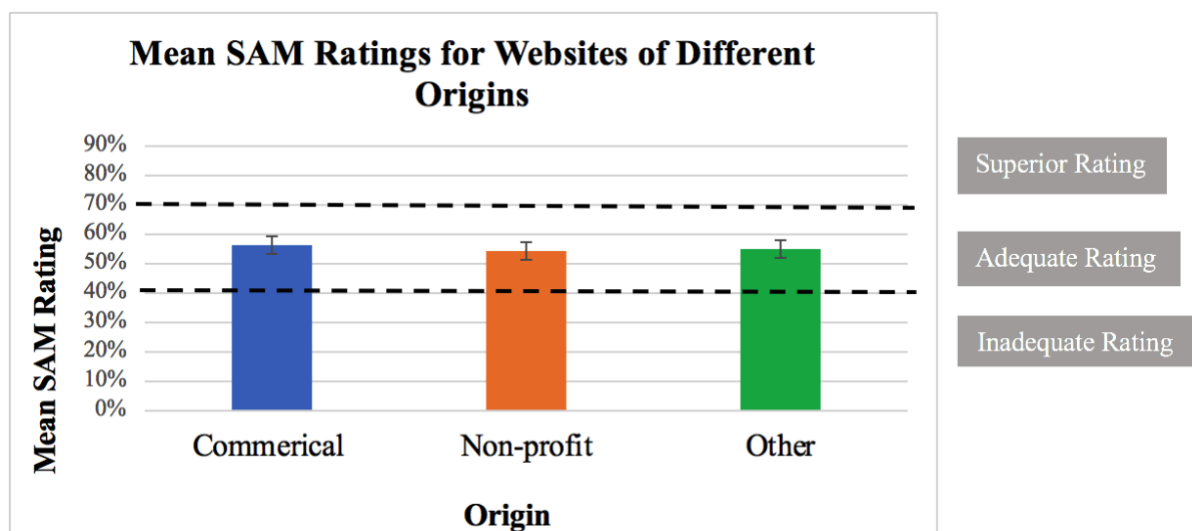
*Note 4: N stands for the number of webpages that received scores of inadequate, adequate or superior, respectively.*

### 3.4 Hypotheses testing

Prior to analyses, the data was examined for skewness, kurtosis, outliers and homogeneity of variance and determined to meet the assumptions of parametric testing.

#### 3.4.1 SAM Ratings for Websites of Different Origins

It was expected that websites of non-profit origin would have significantly higher SAM ratings than websites of commercial or other origin. An ANOVA indicated that there were no significant differences in SAM ratings based on website origin,  $F(2, 34) = .109$ ,  $p = .897$ ,  $\eta_p^2 = .006$ . Therefore, the null hypothesis was supported. This is illustrated in Figure 1.



**Figure 1. Mean SAM Ratings for Websites of Different Origins**

*Note 5: SAM stands for Suitability Assessment Measure. Standard error bars rounded to two decimal places.*

### **3.4.2 SAM and DISCERN Rating Correlation**

A significant relationship was not expected between SAM and DISCERN ratings. A two-tailed Pearson product-moment correlation  $r(35) = .225$ ,  $p = .180$  supported this hypothesis.

A small, positive correlation existed between the two ratings, but this was not significant therefore, the null hypothesis was supported.

### **3.4.3 SAM Ratings and Readability**

A significant negative relationship was expected between SAM ratings and readability (as assessed by RGL). However, a one-tailed Pearson product-correlation,  $r(35) = -.149$ ,  $p = .378$  supported the null hypothesis. A small, negative correlation existed between SAM ratings and RGL, but this was not significant.

## **Chapter 4: Discussion**

### **4.1 Overview**

This study investigated the suitability of online tinnitus information. Results found the mean suitability of online tinnitus information to be adequate. This chapter will discuss the major strengths and areas for improvement identified by this study across the six areas of suitability: content, literacy demand, graphic illustrations, layout and typography, learning stimulation and cultural images and examples. Common areas of greater suitability were literacy demand and some items within layout and typography. Common areas of poorer suitability were content, graphics, learning, stimulation and motivation and cultural images and examples.

The study also analysed the relationships between suitability and three other factors: origin, quality and readability. No particular website origin was found to be creating content of higher suitability than another, neither was higher suitability found to be positively correlated with quality. Additionally, more suitable webpages were not found to be associated with lower readability.

These findings will be discussed in more detail in this chapter as well as the clinical implications of this study, its limitations and suggestions for future research in this area.

### **4.2 Suitability of Online Tinnitus Information**

Suitability analysis of online tinnitus information with the SAM tool found materials to be adequate on a scale of unsuitable, adequate to superior. The mean percentage score is interpreted as less than 39% being not suitable, 40-69% as adequate and 70% and above as superior suitability (Doak et al., 1996). The mean score was in the middle range for the

adequate criteria and the distribution of the scores was tight ( $M = 55\%$ ,  $SD = 11\%$ ) This is reflected by only 2 articles (out of 37) being assessed as superior and 2 (out of 37) being assessed as not suitable.

This overall assessment of suitability found agreement with other suitability studies that also found overall suitability to be adequate. These studies covered vastly different content material from the suitability of hearing aid user guides (Caposecco et al., 2014), health education materials (cancer, stroke and maternal-child relationships) (Ryan et al., 2014), paediatric dental materials (Kang et al., 2005), physical activity handouts (Vallance et al., 2008) to materials on warfarin (Nasser et al., 2012).

Suitability is a key health literacy assessment measure because as previously discussed, if the individual cannot understand the piece of information then they likely will not be prompted to change or adapt their behaviours and act in a self-efficacious manner (Doak et al., 1996). The necessity of tinnitus information being highly suitable is compounded given what is known about individuals with lower health literacy and the complexity of the condition.

Individuals with lower literacy levels are likely to come from lower socioeconomic backgrounds. They are statistically less likely to be able to read and understand health materials and as a result are less likely to take on health information and adapt their health behaviours (Chamberlain & O'Neill, 1998; Leganger & Kraft, 2003; Paxton & Sculthorpe, 1999). Coupled with this, tinnitus is a health condition with variable presentation, that in many cases cannot be treated and management often involves an element of trial and error. Additionally, for many individuals with intrusive tinnitus, a root cause of their tinnitus severity is their focus and preoccupation with the tinnitus that produces a repeating cycle of

annoyance and may also co-occur with mood changes, fear, anxiety, and depression (Henry et al., 2005). Given the level of ambiguity in tinnitus treatment and management, the threat to an individual's quality of life if their tinnitus is severe it is vital that tinnitus information should be suitable, especially to enable individuals with lower literacy to be self-efficacious and achieve the best possible health outcomes. With this in mind, while the overall adequate rating is acceptable, it is reasonable to suggest that to facilitate the best health outcomes for individuals accessing these materials, they should in fact be materials of superior suitability, a rating that only 5.4% of the materials in this study achieved.

The strengths and areas for improvement identified by the SAM will be discussed, as well as recommendations to key stakeholders about how suitability can be improved to better meet the requirements for a superior suitability rating.

#### **4.2.1 Strengths and Areas for Improvement Identified by The SAM**

##### **4.2.1.1 Content**

It is vital that readers understand the main purpose of a health instruction so they do not miss its main points. In most of the materials assessed, the title, cover, or illustrations told the reader the purpose either explicitly or implicitly. However nearly half (43%) of the materials focused on non-behaviour facts (i.e., medical facts) about tinnitus, as opposed to information about how to treat and/or manage tinnitus. Doak et al. (1996) recommend that the majority of the content in any health material should be information aimed how to treat and/or manage the health condition. Non-behaviour information that frequently took up the bulk of the articles included defining what tinnitus is and how the mechanism of tinnitus works. This is problematic because adults usually do not want to learn medical facts about tinnitus, they want to learn behaviour information that will help resolve their tinnitus, such as red flags for

when you should make an appointment to see a doctor or audiologist. However, they cannot change their behaviour if they are not told how to address their health problem or anxiety (Doak et al., 1996).

A vital weakness common among 97.3% of the materials assessed was the absence of a summary or review at the end of the material. This was a similar finding to Ryan et al. (2014) who found that 92.8% of the materials assessed in their study (health education materials on stroke, cancer and maternal-child relationships) included no summary or review. Including this element in all health materials is paramount because some readers may miss these key points on first exposure (Doak et al., 1996). By including a summary, the reader is reminded of the most critical information which reinforces learning (Ryan et al., 2014). Importantly, for encouraging behavioural change, repetition builds self-confidence and skill, which positively reinforces self-efficacy (Doak et al., 1996).

#### **4.2.1.2 Literacy Demand**

For this factor, 3 out of 5 items were assessed as superior: Writing style, sentence construction and use of road signs. Collectively, this means that on average, online tinnitus information is written in a style that is easy to understand through its use of conversational tone and active voice, context is given before the reader is introduced to new information and there is extensive use of headings to tell the reader what is coming next. All of these factors help facilitate the reader's comprehension of what they are reading (Doak et al., 1996). This finding is similar to that of Kang et al. (2005) who evaluated paediatric dental patient education materials and these items were also assessed to be superior for suitability. However, this is the exception to a wider trend where literacy demand generally has been

found to be adequate or not suitable (Caposecco et al., 2014; Nasser et al., 2012; Ryan et al., 2014; Vallance et al., 2008).

Manchaiah et al. (2017) found the mean RGL of the 37 articles assessed to be 11.23, which is unsuitable. It exceeds and is effectively double the recommended RGL of 5 – 6 (Doak et al., 1996; Weiss & Coyne, 1997). This fits with previous studies for example Vallance (2008) and Caposecco et al. (2014) who both found the RGL of health information materials to be unsuitable. According to the SAM evaluation criteria by Doak et al. (1996), RGL is a critical factor in comprehension. Less skilled readers may take words literally, miss the context and meaning, tire quickly and skip or miss words. Because of these factors regardless of overall suitability rating, if an article's RGL is too high (beyond the recommended RGL of 5 – 6), it may be misunderstood and is therefore unsuitable for use.

A quarter (24.3%) of the materials assessed featured extensive use of unsuitable vocabulary. Examples of unsuitable vocabulary include using an uncommon word like “audible” that could have been substituted for a more colloquial word like “hear”. In addition, use of jargon words like vertigo, cochlea and audiogram were used without defining these terms in language a layperson could understand. Finally, value judgements were not explained in practical terms such as “persistent long-term ringing” and “prolonged noise exposure” were not quantified in minutes or hours for the reader (i.e., prolonged noise exposure is 85 decibels or more for 8 hours or more). This finding was nearly identical to the findings of Ryan et al. (2014) who found 23% of vocabulary used in stroke, cancer and maternal-child relationship materials were unsuitable and Vallance (2008) who evaluated the suitability of educational resources for physical activity who found 25% of vocabulary was unsuitable. Caposecco et al. (2014) found nearly half (44%) of all hearing aid user guides to have unsuitable

vocabulary. Use of uncommon words, jargon terms and a lack of practical definition of terms effect an individual's ability to read and understand written information has clear implications for how effectively they may be able to use health information (Laplanche-Lévesque et al., 2012).

It has already been discussed that an individual's health literacy is dependent on many factors, some of which relate to the individual (culture, attitude and motivation) and these can be hard to change. However, aspects of health literacy that are relatively easy to change are those relating to the health information material people with health concerns access in order to learn more about their health condition and/or make decisions about their treatment (The World Health Organisation, 2016). Suitable vocabulary in online tinnitus information is a factor of health literacy that currently is unsuitable and in the grand scheme of things, could be easily changed with an increase in consideration from developers of this information.

#### **4.2.1.3 Graphic Illustrations, Lists, Tables and Charts**

This factor assessed the use of graphic and illustrations throughout the materials. Graphics can be a powerful learning feature and have the potential to facilitate better understanding of tinnitus information. Ratings were largely unsuitable for this factor, but consistent with other research findings. Vallance et al. (2008) found 48.5% of the cover graphics of educational resources for physical activity to be unsuitable, that many illustrations were too technical and confusing and 79% of illustrations and graphics were not captioned. Nasser et al. (2012) found less than half of information about warfarin was adequate for this factor. Ryan et al. (2014) found half of health education materials on stroke, cancer and maternal-child relationships lacked captioning.



For the cover graphics of the materials assessed in this study, 75% had one or two (but not all three) of the following features: (1) is friendly (2) attracts attention (3) clearly portrays the purpose of the materials. There was no consistent combination of features present or missing in the cover graphic. However, it is concerning, that a significant portion online tinnitus information may not be friendly or attention grabbing because the cover image has been found to be a deciding factor in determining an individuals' attitude toward and interest in a piece of health information (Doak et al., 1996).

The use of illustrations in the materials was insufficient with only 40.5% of the articles assessed including illustrations. It is important that where appropriate illustrations are included because combining text with simple pictures can increase patient attention, comprehension, recall and buy-in to the material's message, provided that they understand the elements being reviewed (Houts et al., 2006). Of the materials that included illustrations, 40.9% of these images were found to be unsuitable and 40.9% were found to be superior. Unsuitable images were unfamiliar and complex. For example, medical illustrations such as a drawing of the middle ear system or the cochlea were often used. It is important visuals are very basic and familiar because they are accepted and remembered when they are familiar and easily recognised (Doak et al., 1996). Furthermore, 55.6% of images and graphics were not captioned. This is a missed learning opportunity and source of support for the reader because it is the caption that explains what the graphic is about (Doak et al., 1996). Use of captions are especially important for individuals with low literacy skills to help facilitate their understanding of the information they are reading (Houts et al., 2006).

#### **4.2.1.4 Layout and Typography**

Typography and layout were relative strengths for this factor. All articles used appropriate type size (at least 12 point), sentence case type and appropriate typographic cues. Use of these text features makes reading as easy as possible for readers of all skill levels (Doak et al., 1996). On average, layout was rated as adequate. Layout factors that negatively influenced this rating included line length exceeding 30-50 characters, frequent lack of illustrations, lack of visual cuing devices (shading, boxes or arrows) and the appearance of clutter due to lack of white space on the page. Higher suitability in these two areas of layout and typography have also been common in previous suitability studies (Caposecco et al., 2014; Ryan et al., 2014; Vallance et al., 2008).

Use of subheadings could be improved for this factor. Doak et al. (1996) suggest that 5 is maximum number of independent items that should be under a subheading (and is the criterion for a superior rating for this item) (Doak et al., 1996). While 35% of the articles assessed were superior in their use of subheadings, a large portion (40.5%) were rated as unsuitable (the criteria for an unsuitable rating for this item was more than 7 items without a subheading, or more than 7 items presented under each subheading). Similarly, Vallance et al. (2008) found 53% of educational resources for physical activity were unsuitable. It is important there are no more than 5 items under a subheading as this is the limit of how many independent items most individuals can recall. For individuals with low literacy, the appropriate number of items per subheading may in fact be lower, 3 -5 items per subheading, according to Doak et al. (1996). This is an important item that aims to ensure the key messages of the information are easily flagged to the reader through use of clear subheadings with short, concise chunks of information that can be easily remembered (Doak et al., 1996).

#### **4.2.1.5 Learning Stimulation and Motivation**

This factor assesses the extent to which the material equips and motivates the reader to successfully apply health information to their life and health concern through three items: interaction, modelling and motivation (Caposecco et al., 2014).

Interaction analyses the extent to which the material actively engages the reader with the content through some form of response to a question or problem. Other studies have found this item to be unsuitable. Ryan et al. (2014) reported 56% of education materials for stroke, cancer and maternal-child relationships provided no interaction. Similarly Vallance et al. (2008) reported 48% of physical activity resources provided no interaction. In this study the vast majority (89.2%) of articles provided no interaction which is far greater than the results reported by the previously mentioned studies. This represents a significant missed learning opportunity for the bulk of readers of online tinnitus information. Learning is an active, not a passive process and use of interaction techniques give the reader the best chance to enhance retention of the information they have read and facilitate their learning (Doak et al., 1996).

Modelling assesses how well the material has explained to the reader what the desired behaviour is for them to effectively manage or treat their health concern. Modelling should be explicit and specific i.e. "you must make an appointment to see a doctor or audiologist if your tinnitus is pulsing to the beat of your heart", as opposed to general or abstract. Results for this item were varied. Nearly  $\frac{1}{2}$  of the materials were superior in their modelling and around a  $\frac{1}{4}$  were adequate, however another  $\frac{1}{4}$  were unsuitable. Unsuitable materials often provided no modelling to the reader on tinnitus prevention or management techniques, a concerning finding when many readers' primary aim is to treat their tinnitus. Adequate materials lacked specific and explicit modelling, for example "seek prompt medical care if you have buzzing

in your ear that is persistent or causes you concern” – a reader may be unsure from this who they should seek medical care from exactly. In this case, a GP, ENT or audiologist should have been specified, i.e., “you should make an appointment with your GP, or an ENT or audiologist if you have buzzing in your ear that you are worried about”. Compared to other suitability studies, the quantity of materials with unsuitable modelling was higher (Caposecco et al., 2014; Ryan et al., 2014; Vallance et al., 2008).

In addition to whether an article tries to actively facilitate the reader’s learning and the way desired behaviours are modelled, the amount to which a task is perceived by the reader as “doable” is important for suitability. This is because the more doable a task is perceived, the more likely it is that readers will learn and engage with the health information (Doak et al., 1996). This item is called motivation and is assessed by how well complex topics are subdivided by headings and the extent to which bullet points and small paragraphs are used to facilitate flow and a feeling of success within the reader.

This was a relative strength for online tinnitus information. Around half (51.4%) of the material was rated as superior in this area, 35% was adequate and 13.5% was unsuitable. Unsuitable and adequate materials could be improved with consistent and extensive use of headings to break up large chunks of text into manageable sizes and use of short bullet points when listing points. This spread of suitability found agreement with Vallance et al. (2008) and Ryan et al. (2014). Caposecco et al. (2008) was a slight outlier to this trend, who found a ¼ of hearing aid user guides to be unsuitable for motivation and the rest of the materials assessed to be adequate. The consequence of materials lacking in suitability for this item may be that the desired behaviours seem less achievable (Doak et al., 1996) which may result in a

reduction in motivation, confidence and self-efficacy to tackle the health issue at hand (Caposecco et al., 2014).

Learning stimulation and motivation should be an area of particular focus for key stakeholders of online tinnitus information given that it is these factors in particular that have the ability to facilitate behavioural change and improve health outcomes. Results of this study found that nearly all (89.2%) of materials failed to interact with the reader. Interaction is a valuable learning tool that can help readers to better remember what they have read.

Additionally,  $\frac{1}{4}$  of articles did not provide direct and clear instruction on how to treat or manage their tinnitus. This is an area that must be improved to effectively educate readers on tinnitus symptoms, how to manage them, and who to seek help from.

#### **4.2.1.6 Cultural Images and Examples**

To be accepted, an instruction must present cultural images and examples in realistic and positive ways (Doak et al., 1996). In cases where raters could not identify overt cues as to the culture, this factor was not rated. Absence of overt cultural cues has been noted in two previous studies that used the SAM and in these cases was omitted from assessment (Kang et al., 2005; Vallance et al., 2008).

This study found 10% of materials presented images or examples positively. A third of materials (35%) neutrally represented tinnitus. However, the majority (55%) of materials were unsuitable. Examples of unsuitable images include a picture of a man holding his ear, wincing and looking to be in extreme pain, and use of phrases that victimise the reader (or an individual with tinnitus, if the reader does not have tinnitus themselves), by referring to an individual with tinnitus as a “tinnitus sufferer”. An extreme negative portrayal of tinnitus

included an article with a heading labelled “deaths” that discussed deaths the author directly attributed to tinnitus and the use of sentences such as “two million Americans are debilitated by tinnitus; they can’t work; they can’t sleep. It’s life destroying and a substantial cause of suicide” (Sanders, 2011). While tinnitus is a complex complaint that may present alongside insomnia, depression or anxiety, this is not necessarily a common experience for all individuals with tinnitus (Fackrell et al., 2012). It could be argued that this portrayal is alarmist and for the majority of individuals, inaccurate.

Doak et al. (1996, p. 52) discussed that a material portraying an ethnic group in an inappropriate way is “most surely unsuitable because it is likely to be rejected by members of that ethnic group” and this is a go-no/go signal for suitability, regardless of the overall rating.” It may be reasonable to suggest that this go-no/go policy should extend to an inappropriate (and arguably inaccurate) portrayal of tinnitus, for example materials that make a direct cause and effect correlation between tinnitus and death or suicide. Cultural portrayals such as this may serve to victimise people with tinnitus, as well as stir up a level of fear mongering and may exasperate the feelings of individuals with existing levels of anxiety. Such materials seem to be in direct opposition of the purpose of online information about tinnitus which is to equip individuals seeking information with a realistic attitude towards tinnitus, allow them to be involved in their management and encourage them to make positive behavioural change.

### **4.3 Type of Organisation and Suitability**

Previous analysis on the relationship between suitability of health information and the type of organisations developing health materials has not been published, however this relationship has been analysed for readability and quality.

It was hypothesised that the suitability of online tinnitus information may follow an emerging trend in readability and quality studies established by Cheng and Dunn (2015), Kieran et al. (2010) and Laplante-Lévesque et al. (2012). These researchers have found materials developed by non-profit organisations are of higher suitability. However, this study found no significant correlation between the suitability of an article and its origin. This study took its data set from Manchaiah et al. (2017) who were an outlier to the wider trend and also found no correlation between readability and quality of online tinnitus information and their origin. It is possible that this is a trend unique to this data set and further studies are required to further investigate any correlation between origin and suitability.

However, if these results are taken at face value, websites of commercial, non-profit and government origin may be benefitting from undeserved and incorrect biases and this is important for health professionals and consumers alike to be aware of. It is possible that websites of commercial and non-profit origins benefit from a general bias towards them being of higher quality because as already discussed some researchers hypothesise that websites from commercial, university, and government origins may be of higher quality than personal webpages or blogs due to higher resources to spend on website development (Manchaiah et al., 2017). It is reasonable to hypothesise that this may be a view held by medical professionals and consumers alike, not just researchers.

Additionally, government websites are likely to benefit from organisational credibility, whereby these sites are believed by consumers to be trustworthy (Goldsmith et al., 2000) and materials produced by government departments are likely to be a preferred source of information for many users of health information online (Pletneva et al., 2011). Education for

individuals and professionals on these points about online tinnitus information is crucial. Undoubtedly these biases have some influence on which articles readers access and while these biases lead them to believe that by accessing information produced by government websites they are better meeting their health needs, this may not be the case.

#### **4.4 Suitability and Quality**

No significant association between suitability (SAM rating) and quality (DISCERN) was noted. Nasser et al. (2012) also analysed the relationship between suitability and quality. They did not report the level of significance between the two measures, although they reported some degree of negative association in that an article on warfarin may score poorly for suitability but score highly for quality. However, the strength of this relationship is not known.

Suitability considers the literacy requirements of a material, its graphics and layout and how a material attempts to facilitate behavioural change. However, it provides no assessment about the accuracy of the information, information that is provided by a quality assessment. This provides justification for analysis of both quality and suitability as they provide separate analyses and different information that is important for a full and complete picture of how well a piece of information may facilitate patient health outcomes. This point is further strengthened by this study's findings that there is no significant correlation between suitability and quality ratings.

#### **4.5 Suitability and Readability**

The creators of the SAM, Doak et al. (1996) reported that if readability is high (difficult) then the suitability is usually low (less suitable). The readability of the materials included in this



study was high, with at least 10-12 years of education required to read and understand them. However, the suitability of these materials was found to be adequate and no significant relationship between the two factors was identified. Like the findings for suitability and quality, these results provide clear justification for separate readability and suitability analysis.

Results finding low readability with high suitability would reflect developers taking both factors into account to facilitate comprehension of the content. However, the results of this study may indicate a lack of awareness of readability on the part of the developers.

Practically this means that for individuals with lower literacy skills, comprehension will be difficult (due to high readability) however these materials may have adequate potential to facilitate the readers' understanding of the information and encourage self-efficacy (due to adequate suitability). However, Doak et al. (1996) consider readability to be a go-no/go signal for suitability, regardless of the overall rating. They believe it predicts an individual's overall comprehension of the material and if individuals are provided with information with a RGL that exceeds their ability, miscommunication and misinformation is likely, regardless of the suitability level. Ultimately, if a material on tinnitus cannot be properly comprehended then it is not doing its job because it can only be effective in improving health outcomes if it is understood by the reader. For developers of online tinnitus information, producing materials with superior suitability as well as low readability must become a priority.

#### **4.6 Broader Implications**

This study's findings are important because they have the potential to facilitate better health outcomes for individuals accessing online information on the cause of tinnitus, its symptoms, diagnosis and treatment options. It is reasonable to suggest that there is a significant number

of individuals searching for online tinnitus information given the high use of the internet for health information (Susannah Fox & Duggan, 2013; Ybarra & Suman, 2006) and that the majority of individuals with tinnitus do not seek advice from their GP (Attias et al., 1995). This finding lends its self towards the conclusion that many individuals are self-managing their condition, a process in which accessible online information is critical give the role the internet plays as a “first line of support” to help self-manage tinnitus symptoms (Department of Health, 2009, p. 17).

Overall materials were found to be adequate. However, it is concerning that only 2 out of 37 articles gained a superior rating. The features of a superior rating should be the standard that online tinnitus materials are developed to be. The implications of this is that materials of poorer suitability (unsuitable and adequate) may be a contributing factor towards poorer health outcomes, particularly for individuals of lower socioeconomic backgrounds. It could be argued that because individuals of lower SES backgrounds are the least likely to use online health information, then lesser suitability does not matter. The reasoning for this being that currently most individuals using online health information are not from lower SES backgrounds, they are from higher SES backgrounds (Andreassen et al., 2007; Susannah Fox & Duggan, 2013) and are likely to have the skills to read and use information online tinnitus information, even if it is of less than optimum suitability.

This disparity reflects known social, economic and cultural inequalities present both in the on and offline world (Van Dijk, 2005; Zillien & Hargittai, 2009). Lack of computer access and network connection is commonly used to explain this inequality in internet use and access however it is only one of four barriers to access that contribute to the so called “digital divide” between low and high SES individuals. The barriers also include, (2) a lack of basic

digital experience caused by lack of interest, computer anxiety, and unattractiveness of the new technology, (3) a lack of digital skills caused by insufficient user-friendliness and inadequate education or social support and (4) a lack of significant usage opportunities (Van Dijk & Hacker, 2003, pp. 315-316). The third point, lack of digital skill, encompasses literacy skill in all forms: functional, health and eHealth literacy. Literacy is correlated to use of the internet for health information and additionally, literacy, SES and health outcomes are also strongly correlated (Graham, 2002; The World Health Organisation, 2013).

Therefore, the internet is not only a passive reflection of the known inequalities between these two groups but in the case of production of inadequate health materials, it can be an active reproducer and reinforcer (Norris, 2001; Van Dijk, 2005). By producing materials of the current suitability, individuals from lower SES backgrounds may be digitally falling behind (Dutton, Helsper, & Gerber, 2011) and disadvantaged when it comes to online health information. Therefore, lesser suitability does matter and acting on the findings of this study could be a factor towards reducing this inequality of use and the digital divide.

Suitability assessment, with a tool like the SAM, provides an assessment of how likely a reader is to understand, accept and act on online tinnitus information and can be used to improve these materials. In doing so, this may improve health outcomes which is especially important for those with lower literacy skill and resources. Online health information for many is the only health resource they may utilise to try to manage their tinnitus, or it may be a low-cost resource for health information, compared with seeing a GP or audiologist. With appropriate literacy demands, layout and formatting and sufficient motivation, online information on tinnitus could be an effective tool, useable for everyone, to help those with tinnitus.

#### 4.6.1 Recommendations for How to Improve the Suitability of Online Tinnitus Information

Table 5 discusses the major weaknesses in the suitability of online tinnitus information.

Practically, these findings have implications for two main stakeholders: developers of online tinnitus information and healthcare professionals directing their patients towards articles online.

**Table 5. Major weakness of the suitability online tinnitus information and recommendations for improvement (Doak et al., 1996)**

<b>Factor</b>	<b>Description</b>	<b>Recommendation</b>
<b>Content</b>		
Content about behaviours	Insufficient ratio of information on how to treat/manage tinnitus compared to information on the pathology of tinnitus	Limit information about the pathology of tinnitus. The majority of the content should focus on how to manage tinnitus. This type of information is most important to the reader.
Summary	No summary section in 97.3% of articles	Always provide a bullet point summary of the most important points, preferably no more than 5 points.
<b>Literacy Demand</b>		

Vocabulary	High use of jargon and medical terminology, uncommon terms and unquantified value judgement statements.	Clearly define terms that will be new to the reader at the outset. Only use common English words. Always quantify value judgement statements.
<b>Graphics</b>		
Type of illustration	40% of illustrations unfamiliar and complex	Illustrations should be simple (i.e. line drawings <i>not</i> photographs) and familiar (no use of medical symbols or diagrams, these are unfamiliar and complicated).
Relevance of illustration	Lack of illustrations	Use simple and familiar illustrations to present key messages visually.
Captions	55% of pictures/graphics not captioned	Use captions to tell the reader what the image/graphic is about and where to look.
<b>Layout and Typography</b>		
Subheadings	Insufficient use of subheadings	Use subheadings throughout the material. No more than 5 items per subheading.

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**Learning, Stimulation and****Motivation**

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Interaction	89.2% of articles provided  no interaction	Ask readers to apply their  learning by presenting them  with problems to solve or  choices to make.
Behaviours are modelled and specific	24.3% of articles provided  no modelling to the reader  on how to prevent tinnitus or manage its symptoms; some modelling not specific  enough.	Use familiar and specific language so the reader knows the exact steps to take to address their health issue. Use of pronouns is suggested. I.e. “if <i>you</i> have ringing in your ears that bothers <i>you</i> , make an appointment with <i>your</i> GP.

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**Cultural Appropriateness**

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Cultural images and examples	Negative portrayal of experience of tinnitus in text  and in pictures	Do not use pictures that are negative (i.e. if they show people wincing or holding their ears in pain). Pictures should send a positive message. Use positive descriptions i.e. ‘person with tinnitus’ <i>not</i> ‘tinnitus sufferer’.
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#### **4.6.1.1 Recommendations for Developers**

Developers should allocate time and thought to improve the suitability of the online tinnitus information they develop. Table 5 is directly applicable for developers and formatters of future online content, as well as developers who wish to adapt their current materials to better meet these recommendations and increase suitability.

When a piece of health information is produced a focus on producing a material of superior suitability must be a focus from the early conception phase – not as a final consideration with acceptance that adequate suitability is acceptable, that it is culturally unsuitable or that readability is too high.

Two general areas for developers to easily improve suitability in are the interplay between formatting and the materials message and the vocabulary used. Kang et al. (2005) discussed that often materials are developed by a content expert and then further developed and formatted by media specialists. The end result may be a material with general aesthetic appeal however there may be no connection between the information and the images (i.e., 40% of illustrations were unfamiliar and complex), the images chosen may portray tinnitus negatively or there may be insufficient use of subheadings to warn the reader what information is coming up next. In these cases, the suitability of the material can be highly variable. Additionally as previously discussed, the difficulty for health professionals trying to communicate health information is their choice of vocabulary that most patients are unfamiliar with. However, from the health professionals' perspective using this technical, medical vocabulary allows them to be precise and specific. Both these points must be reconciled with individuals' literacy and suitability needs and preferences. To improve the

suitability of the formatting, more cohesion is required between the experts who develop the content and who format the content to ensure the message and the images are better connected.

Vallance et al. (2008) has previously recommended that the development and testing stage should involve the target population to pre-test the resource with a sample target audience to assess suitability. This may be something developers should consider. It is especially important that layout choices facilitate the readers understanding as opposed to distracting them, because distraction can compound the process of reading and understanding health information if it is complex or difficult to understand (Ryan et al., 2014). The benefits of improving these aspects of suitability include improved comprehension and shorter reading time (T. Davis et al., 1996). In fact patients across the spectrum of literacy skill and education levels prefer health information that is written in simple language and with simple design features over more complex and densely written materials (T. Davis et al., 1996; Ryan et al., 2014). Additionally, while a large portion of individuals seek out information designed for professionals because they want to access information they believe is the most comprehensive (C. Boyer et al., 2002), plain and simple language must be the gold standard of language. However, developers may wish to consider providing a referral to additional resources for this population.

In adopting the recommendations from this study, developers of online tinnitus information may be helping to improve the health outcomes of individuals with tinnitus and making information more effective, especially for those with lower literacy skills. This is especially important as the majority of individuals with tinnitus do not seek the help of a hearing professional. Many individuals with tinnitus are likely getting their information on tinnitus



from the internet and self-managing their condition. The success of their self-management is important as tinnitus is often a long-term condition and if the information they access online is effective, this can facilitate acceptance, learning to live well alongside the consequences of their symptoms and improved health outcomes (Coleman & Newton, 2005). Often the content they need to be provided is relatively simple and straight forward. Often effective informational counselling on topics such as, what is tinnitus, understanding that many people experience it (to normalize their experience), and suggestions about how to minimize its impact, is sufficient treatment for many individuals (Department of Health, 2009).

#### **4.6.1.2 Recommendations for GPs and Hearing Professionals**

A minority of individuals with tinnitus will seek help from their GP or a hearing professional like an audiologist. However, those who do seek help from these professionals are likely to be in the 1-2% of the population whose tinnitus is continually intrusive and seriously impacting quality of life (S. C. Brown, 1990; A. Davis, 1995; Hinchcliffe, 1961; Leske, 1981; Sindhusake et al., 2003). These patients may also present to a professional feeling like they are in a state of crisis. This is a feeling which individuals have previously reported to trigger their decision to see a GP for help and information instead of the internet (Susannah Fox & Duggan, 2013). When they see a GP, it is common practice for GPs to direct their patients towards online information about tinnitus in combination with providing counselling about tinnitus (El-Shunnar et al., 2011; Fackrell et al., 2012). These patients may be in heightened emotional states and their quality of life may be seriously affected. Therefore it is important that any websites they are directed to are of superior suitability that they can easily understand, accept and act on to effectively improve their quality of life.

Given this, it is important GPs and hearing professionals are aware of common weakness in the suitability of online tinnitus information, seen in Table 5, and if they exist in the materials they recommend. If so, these areas could be improved by adding supplemental instructions to a material or highlighting the most important points and/or behaviour information. They can also screen for appropriate RGL and realistic and positive cultural representations, measures that are go-no/go signals in terms of suitability, regardless of overall rating (Doak et al., 1996).

GPs and hearing professionals should additionally be aware of unconscious bias they may hold towards materials of government or non-profit organisations (Goldsmith et al., 2000; Manchaiah et al., 2017; Pletneva et al., 2011). Health professional must actively and purposefully make sure an article is suitable, they cannot assume it to be so because of an article's origin.

Promotion of awareness of suitability among GPs and hearing professionals may also be necessary as general knowledge of patient health literacy levels and the implications of health literacy was found to be limited in a 2013 study by Atcherson, Zraick, and Hadden. This study found that some audiologists and speech-language pathologists were either somewhat or not aware of the average US RGL and its impact on the readability of forms in their clinics. It is possible this lack of awareness extends to knowledge of suitability and its impacts.

#### **4.7 Limitations and Future Research**

This study has several limitations. First, this study takes its data set from Manchaiah et al. (2017) who collected data from only one search engine, Google ([www.google.com](http://www.google.com)), because

it is the most commonly used search engine (Susannah Fox & Duggan, 2013). However, this does not represent all potential search methods and future research may want to include other major search engines such as Yahoo and Bing. Second, key words (tinnitus, ringing in the ear and buzzing in the ear) were used to identify common searches; however it is possible that searchers would in fact use different search terms, come up with different results and therefore access different articles than those used in this study.

Third, the SAM is a tool specifically developed to evaluate printed material, however was utilised to evaluate online material for this study. As a result there are some features unique to online health information, such as connectivity and multimedia, but that are not evaluated by the SAM. Additional information provided by connective features within the materials assessed such as hypertext or hyperlinks were not assessed. With this in mind, Beaunoyer, Arsenault, Lomanowska and Guitton (2017) suggest additional suitability assessment should be allocated to assess supplementary information provided by the target webpage.

Additionally, multimedia material like videos embedded in the webpages were not assessed, however they may have provided effective information, especially considering some individuals prefer information provided in a video or audio format rather than as text (Beaunoyer et al., 2017). Future studies may wish to develop additional assessment for these features.

Fourth, the readability measures used by Manchaiah et al. (2017) (F-K and SMOG) are two commonly used measures; however these two readability formulas do not assess all the dimensions related to the reading process therefore for future studies, other readability measures or a comprehension test could be used to investigate a fuller picture of patient access and understanding (Meade & Smith, 1991).

Fifth, although inter-rater agreement met the criteria for excellent agreement beyond chance, the scoring process for the SAM has elements of subjectivity for most criteria which may have introduced variability in the scoring (Nasser et al., 2012; Vallance et al., 2008). Fifth, this study only evaluated English materials, therefore the suitability findings may not generalise to websites written in other languages. Future studies may wish to investigate the suitability of online tinnitus information in other languages.

Sixth, this study did not cover an element of health literacy assessment called content accuracy, a measure which could assess the breadth of misinformation within online tinnitus information. Given the known risk for misinformation online, the vulnerability of some individuals with tinnitus and the dependency of many on the accuracy of this information to effectively self-manage their condition, this would be a useful aspect of health literacy to investigate further in the future.

Vallance et al. (2008) have previously discussed the need for randomised control trials to quantify whether more suitable resources (determined by the SAM) do in fact enhance knowledge, attitudes, skills and behaviours resulting in improved health outcomes. Future research could focus on the impact of revising tinnitus-related material.

This study assessed the suitability of tinnitus information that was online, however did not include social media sites such as YouTube and Facebook pages and groups. Use of social media by individuals with chronic conditions to access information, support and empowerment is established in the literature. Therefore, future suitability assessment should be considered for social media.

It is also worth mentioning that in approximately a year between the time of the original Manchaiah et al. (2017) study and the present study, eight of the forty five links were no longer active. Online health information is constantly changing and while these results may be true for near future, the suitability of online tinnitus health information will not be sedentary.

To date there are no other studies that have assessed the suitability of online tinnitus information. Therefore, these results cannot be compared to that of others to check for consistency of results. It has already been discussed however that this study found common strengths and weaknesses of suitability when compared to other studies in the areas of hearing aid user guides (Caposecco et al., 2014), health education materials (cancer, stroke and maternal-child relationships) (Ryan et al., 2014), paediatric dental materials (Kang et al., 2005), physical activity handouts (Vallance et al., 2008) and materials on warfarin (Nasser et al., 2012). Future research may wish to continue investigating the suitability of online tinnitus information.

## **4.8 Conclusions**

Worldwide the internet has become an important tool for many individuals to help resolve and self-manage health issues, either for themselves, friends or family. An internet search may be a primary source of information when the health concern is non-life threatening or may act as a quasi-screen to see if a trip to the GP or another health professional is justified. For individuals from lower SES backgrounds, this health resource may be very useful as internet access is increasingly a cheaper health solution compared to a consultation with a GP or health professional.

However, the usefulness of online information is limited by challenges associated with health literacy. The purpose of this study was to investigate the suitability (a key health literacy measure) of online tinnitus information identified and assessed by Manchaiah et al. (2017). The suitability of online tinnitus information on average was found to be adequate, so far there have been no other studies assessing the suitability of tinnitus information, on or off-line, that these results could be compared with. Consistency was displayed however between this and other suitability studies in terms of overall suitability rating and in specific areas where suitability was poorer: content, graphics, learning, stimulation and motivation and cultural images and examples.

Currently a standardised protocol for tinnitus treatment is lacking and treatment can be trial and error to see which management option works best for each individual. As a result, GPs, hearing specialists, patients and whānau must practice effective patient centred care and shared decision making as they may regularly revisit intervention plans and reconsider options dependent on the severity of their tinnitus and the evolution of any co-occurring hearing impairment (Laplante-Lévesque et al., 2010). However while there is an increasing amount of literature from academics and organisations like The World Health Organisation (2016) emphasising the large role an individual's health literacy plays in their health outcomes, developers and practitioners have been slow to adapt health materials to better meet health consumers' needs (Ryan et al., 2014). Additionally, it is known that not all individuals accessing online tinnitus information will be equipped with the skills required to access, process, and understand complex tinnitus information (i.e. information of unsuitable or adequate suitability).

Therefore, developers of online tinnitus material are recommended to develop materials of superior suitability and health professionals are encouraged to provide materials of superior suitability to allow equity of outcome, for individuals regardless of their health literacy. By developing and using information that is suitable, there is greater potential for individuals with tinnitus and their whānau to effectively inform themselves, manage their symptoms and improve their health outcome, especially for individuals with lower health and eHealth literacy.

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